EFFECTS OF COMMUNICATION COMPLEXITY ON ANALOGUE CLIENTS IN A VIDEO CANCER GENETIC COUNSELING SESSION

By

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ABSTRACT

Objective: Communication of information plays a central role in genetic counseling. There have been few direct comparisons of differing communication approaches. This research study aimed to experimentally manipulate communication of genetic information and to describe how the complexity of counselor communication impacts client affective and cognitive outcomes using a hypothetical cancer genetic counseling scenario.

Methods: The study used a mixed methods experimental design consisting of a web-based module that simulated specific educational and communication aspects of a cancer genetic counseling session. Female study participants (N=286) were randomly assigned to watch one of three simulated video genetic counselor sessions of either high, medium, or low communication complexity consisting of 8-21 minute of short video clips. Demographic information, personal perceived cancer risk, genetic literacy, and patient-provider orientation were collected before beginning the videos, and survey instruments were administered after the videos to capture decisional, affective, and cognitive outcomes.

Results: Low complexity communication of information reduced feelings of negative emotion (including confusion) compared to the high complexity group. Individuals in the medium complexity group felt more decisional conflict than the high complexity group. No other main effects on measured genetic counseling outcomes were detected. Genetic literacy and patient-provider orientation had modifying effects on the relationship between complexity level and some outcomes. Personal characteristics, including age, race, perceived personal risk of cancer, genetic literacy, and patient-provider orientation were associated with some genetic counseling outcomes. Participants generally found the experience to be realistic.

Conclusions: Low complexity communication did not elicit poorer outcomes than high complexity communication overall. Our findings also support the notion that personal factors influence clients' reactions to genetic counseling communication. In accordance with principles of patient-centered communication, it is important to tailor communication to fit clients' needs.

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INTRODUCTION

Background

In the genetic counseling setting, patients are counseled about the biomedical and psychosocial implications of genetic conditions. Though "education about inheritance, testing, management, prevention, resources and research" is included in the National Society of Genetic Counselor's professional definition of genetic counseling, the effects of communication of information on patients have not been well studied (Resta et al., 2006). Additionally, what goes on in a genetic counseling session has been described as "a black box," and much of genetic counseling practice remains largely unknown, though research using audio and video recordings of genetic counseling sessions has shed light on the typical content of routine genetic counseling sessions (Biesecker and Peters, 2001; Roter et al., 2006). These studies have suggested that genetic counselors talk more than their clients, and the majority of genetic counseling sessions focus on teaching and biomedical information (Meiser et al., 2008; Roter et al., 2006). In genetic counseling, complex information is communicated regarding inheritance, genetics, testing technologies, test results, treatment, screening, medical management, and psychosocial implications of a risk of a disease. Genetic counseling is not only information laden, but information may be provided in a way that is too complex for some clients to understand (Roter et al., 2007). Clearly, communication of information is critical to genetic counseling; Hsia goes as far as to suggest that, compared to other medical contexts, "information giving [is] the treatment itself" in genetic health care (Hsia, 1979). Given this, it is important to better understand how communication of information is affecting patients.

Despite communication of information accounting for the majority of time spent in genetic counseling sessions, not much is known about how the *way* information is communicated impacts how patients feel and think or how it impacts their decisions. Specifically, there have been no tightly controlled experiments designed to examine the effects of providing genetic counseling-related information by altering communication complexity. This study has aimed to experimentally examine participants' responses across varying levels of communication complexity in a hypothetical simulated cancer genetic counseling setting. The purpose of the study was to better understand how communication of information affects genetic counseling patients' affective and cognitive outcomes, to examine how personal characteristics interact with communication complexity to affect affective and cognitive outcomes, and to gather exploratory data about the personal experience of receiving complex information in genetic counseling.

Communication Models and Barriers to Effective Communication in Genetics

Communication of information from provider (i.e., genetic counselor) to patient is the central interest of our study. One model of communication of information is the information-giving model of care, which proposes that the communication of the information is the provider's job, and the decision-making task is the patient's responsibility (Redsell and Buck, 2009). Redsell and Buck emphasize that the "information giving model... assumes that information is understood by everyone in the same manner," and that it is based on "a view that people make conscious, rational choices about health behaviors and that factual information alone will influence choices,"

(Redsell and Buck, 2009). However, not much is known about how much information is needed in order to be "complete" or what specific pieces of knowledge are crucial for any given person's decisions. Moreover, patient informational needs and information-seeking behaviors differ between individuals (Schmidlen et al., 2014; Waters et al., 2016).

In contrast to the information giving model, the patient-centered care model focuses on the personal informational and psychological needs of the individual patient. Patient-centered information provision focuses on making information accessible to patients and includes elements of information chunking, interactivity, plain language and lower oral literacy demand, and empathic statements (Windover et al., 2014; Street et al., 2009; Doak et al., 1996; Roter et al., 2007). Genetics information is complex and often new to patients. Optimal learning necessitates attention to how information is presented and how clients engage with the information. Accessibility of information is another component of patient-centered care, and patients with lower health and genetic literacy will have a more difficult time accessing information than those with higher literacy levels. Additionally, genetics jargon can be a barrier for patients to comprehend the utility of what they are learning. For instance, patients may confuse a biologically functional protein and dietary protein and their relationship to genetics and health (Bernhardt, 2016). One study by Lerman and colleagues found that 49.5% of their cohort of cancer patients left the session feeling confused and feeling that they had difficulty understanding the information (Lerman et al., 1993). To elucidate approaches to remedying problems with accessibility, patient educational research has shown that information is more accessible when presented in chunks and when engagement with the information is encouraged (Windover et al., 2014; Doak et al., 1996). The patient-

centered care and communication model allows for flexibility in tailoring information-giving to each particular patient to meet his or her learning needs.

There is evidence of a mismatch between the informational needs of at least some patients and the informational goals of genetic counselors. One study done in cancer risk counseling with underserved patients at a large healthcare system in California found that ineffective communication stemmed from a number of factors including: "(1) too much information; (2) complex terminology and conceptually difficult presentation of information; (3) information perceived as not relevant by the patient; (4) unintentional inhibition of patient engagement and question- asking; (5) vague discussions of screening and prevention recommendations" (Joseph et al., 2017). This study and others highlight the need for evidenced-based strategies for communication of information in genetic counseling, with a particular need to better understand the roles of language complexity, interactivity, and learning-enhancing communication strategies (Vogel, Leonhart, and Helmes, 2009; Roberts et al., 1994; Takayama, Yamazaki, and Katsumata, 2001; Wang et al., 2005).

Genetic Counseling Communication

Many health care settings, including the genetic counseling setting, involve provider-led communication and information giving. One study aimed to examine aspects of genetic counseling communication and interaction to capture "typical" genetic counseling in practice. By using standardized simulated clients, the Genetic Counseling Video Project (GCVP) videotaped genetic counselors providing genetic counseling in both hypothetical prenatal and cancer settings. Data from the GCVP and from other audio

recording studies, as well as from systematic reviews of research of the content and process of genetic counseling communication have found that genetic counselors are verbally dominant, talking three times as much as their clients (Meiser et al., 2008; Paul et al., 2015; Roter et al., 2006). Genetic counselors are largely in control of the session, and their communication style has been suggested to have a larger impact on the session communication than individual patient characteristics (Pieterse et al., 2005; Ellington et al., 2005).

Within the genetic counseling session, the GCVP found that largest category of talk (56% of all talk) was spent on information provision, with almost 85% of that talk falling into the biomedical rather than the psychosocial domain (Roter et al,2006). This aligns with other research that suggests that biomedical, rather than psychosocial information is the focus of most genetic counseling sessions (Roter et al., 2006; Roter et al., 2008; Paul et al., 2015).

The GCVP study also found that sessions with a higher proportion of technical terms or jargon had lower interactivity with the client (Roter et al., 2007). Interestingly, the self-ratings of genetic counselors' informativeness were found to be inversely related to their use of medical jargon (Roter et al., 2007). Genetics providers are responsible for how much information is given and in what way it is delivered (Paul et al., 2015), but the "standard of care" communication also likely differs from specialty to specialty, as undiagnosed disease counseling requires different educational and informational content compared to a more common disease context such as breast cancer. Additionally, communication may depend on the institutional setting and characteristics of the individual counselor.

Genetic Counseling for Hereditary Cancer Syndromes

In the US, according to the Centers for Disease Control, cancer is the second leading cause of mortality (behind heart disease), and close to 600,00 people die each year die from cancer (CDC, 2014). Between one in two and one in three women will get cancer in their lifetime, and of all forms of cancer, 5-10% are considered to be strongly hereditary (Schneider, 2012). Technological and scientific advancements in testing methodologies and understanding of cancer-associated genetic variants, as well as public awareness of genetic implications in cancer continue to expand the field of cancer genetic counseling. As of 2016, cancer genetic counseling has grown to be the most common genetic counseling specialty in the US, accounting for 48% of the genetic counselors that see patients (NSGC, 2016). This represents a dramatic increase from just 29% in 2014 (NSGC, 2016).

Pre-test cancer genetic counseling sessions may include discussion of the genetics of breast cancer, inheritance patterns, surgical decisions, screening recommendations and risks for multiple types of cancers associated with specific cancer predisposition genes (Berliner et al., 2013). As the science advances, genetic counselors must consider how to adapt the depth and breadth of information presented, and one recent mixed-methods survey study suggests that counselors are "spending more time counseling about uncertainty" as testing options and the likelihood of uncertain results increase (Hooker et al., 2017). The relatively high prevalence and thus high awareness of cancer support the feasibility of a broad range of research designs, including hypothetical designs to examine the role of communication in genetic counseling.

Genetic Counseling Outcomes

While there is a lack of agreement about the most appropriate outcomes of genetic counseling to measure, a number of outcomes have historically been considered, measured, and researched. One rapid systematic review of outcome studies in genetic counseling reviewed 23 studies that met their inclusion criteria and found that common reported outcomes of genetic counseling include: knowledge, anxiety and distress, satisfaction, perceived risk, genetic testing intention or receipt, health behaviors, and decisional conflict (Madlensky et al., 2017). This study also found that from those studies, which were primarily in cancer genetic counseling, genetic counseling has been suggested to increase knowledge, perceived personal control, positive health behaviors, and risk perception accuracy, and to decrease short-term anxiety, cancer-related worry, and decisional conflict (Madlensky et al., 2017). A systematic review of randomized control trials (RCTs) in genetic counseling reviewed 58 publications of 54 RCTs which were also primarily from cancer genetic counseling that assessed "enhancements" to genetic counseling or compared multiple delivery modes (Athens et al., 2017). The review similarly found that common reported outcomes included: psychological wellbeing, knowledge, perceived risk, and patient satisfaction. However, the review noted that "disparate validated and reliable scales and other assessments were often used to evaluate the same outcome(s)," which makes comparison of findings across studies more difficult and less generalizable. Longer term outcomes such as coping, adaptation, and adjustment to a genetic diagnosis have also been measured. Broadly, genetic counseling outcomes include cognitive, affective and decisional outcomes and the preponderance of evidence points toward impact on shorter term outcomes.

Client Personal Characteristics

In medicine--and genetic counseling--patients' inherent personal factors and characteristics contribute to how they respond to information, how they engage in their healthcare, and how they think and feel after their clinical encounter. However, more research is needed to better understand whether and to what degree personal factors impact outcomes. Demographic factors such as race, sex, socioeconomic status, age, and other characteristics have been suggested to make a difference in the decisions patients make, their emotional reactions to, and their degree of engagement in a medical setting (Kaphingst et al., 2016; Cooper & Roter, 2003). In the breast cancer setting, African American women have been less likely to pursue testing, and have been found to be less likely to follow through with recommended screening guidelines than Caucasian women (Armstrong et al., 2005; Butrick et al., 2015; Cragun et al., 2015). By looking for associations between demographic factors of research participants and genetic counseling outcomes, researchers may be better able to understand differences in responses to communication of information.

Genetic Literacy

In healthcare, health literacy, or the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" can impact short and long-term outcomes for patients, including engagement in their care (HHS, 2000). Kaphingst and colleagues studied 624 patients in primary care at a large urban hospital that serves underserved populations, and found that genetic knowledge, health literacy, self-efficacy, and communication were all related to differences in perceived importance of genetic

information and family health history (Kaphingst et al., 2016). Another study in a colorectal cancer cohort found that those with lower health literacy were less likely to receive chemotherapy than those with higher health literacy (Busch et al., 2015).

Genetic literacy has been defined as a subset of health literacy and "the ability of an individual to understand concepts important to the use of personal genetic information" (Erby et al. 2008). In genetics health care, genetic literacy can impact clients' perceptions, decisions, and outcomes. In a study looking at perceptions of 257 individuals with inflammatory bowel disease, those with higher genetic literacy had higher appraisals of the utility of genetic testing for IBD than those with lower genetic literacy (Hooker et al., 2014). Genetics information is often complex and unfamiliar to individuals who have had little to no prior exposure to genetics education. When patients and clients are faced with making nuanced informed decisions in genetic counseling, low genetic literacy can be a barrier to fully engaging in the information and considering how that information may impact their lives.

Patient-Provider Orientation

Patients have preferences about their interactions with providers that can affect how those interactions unfold as well as how satisfied patients are after receiving care. Preferences about providers, such as how directive or "paternalistic" patients expect or want their providers to be can differ from one patient to the next (Redsell and Buck, 2009). One framework for patient-provider orientation considers this characteristic across a spectrum from "disease-" or "doctor-centered" to "patient-centered" (Krupat et al., 2000). When the model of healthcare from the provider matches with the patient's

patient-provider orientation, satisfaction with care has been shown to be higher (Krupat, et al., 2000).

In the health setting, just as the client brings his or her own characteristics into the clinical encounter, so does the provider. The provider may or may not have a communication style that aligns with the patient's preferred orientation. In addition, implicit biases (racial and otherwise), provider goals for the session, communication style, focus on patient-centered care (including partnering language), and beliefs about the importance of specific information are among the factors that may vary across providers. It is important for patient-provider interaction studies to consider how patient characteristics--including demographic characteristics, genetic literacy and patient-provider orientation--affect patient outcomes, as well as to separately consider how patient characteristics and provider characteristics contribute to outcomes. There are many variables to consider, necessitating creativity in study design.

Hypothetical Study Designs with Analogue Clients

Rather than observing a traditional genetic counseling session and controlling for multiple in-session variables, an analogue client (study participant) can be given an experimentally controlled hypothetical scenario and can be asked to act and respond to questions as if the scenario applied to him or her. The use of an analogue client or patient allows for manipulation of one or more content or process elements that would be difficult to manipulate in an in-person medical (or other) interaction. Hypothetical vignettes have been described as "useful research tools yielding valuable data when studying people's attitudes, perceptions and beliefs" (Hughes, et al., 2002), and one review of 18 experimental video-vignette studies found that this method proved to be an

effective way to manipulate communication, that vignettes in well-designed studies are perceived to be realistic, and that observers or participants in these scenarios are able to put themselves into the scenarios (Hillen et al., 2013). Persky and colleagues reviewed 38 analogue studies to assess the hypothetical scenario methodology in genetic susceptibility testing, and their summary suggests that this methodology can be a useful tool, as long as rigorous scientific research design is upheld (Persky et al., 2007). The use of video technologies to experimentally manipulate aspects of healthcare interactions allows researchers to isolate specific parts of communication to examine their effects on analogue clients, and this methodology has been used in a growing number of patient-provider communication studies, including studies examining information recall in the oncology setting (Medendorp et al, 2017).

SPECIFIC AIMS AND HYPOTHESES

The objectives of this study were to experimentally examine the relationships between the style of genetics information provision by genetic counselors and analogue client decisional and affective outcomes, as well as to examine relationships between analogue client-specific characteristics and those outcomes. To capture the effects of communication complexity on genetic counseling outcomes, elements of adult learning theories and oral literacy demand were used to develop three levels of communication complexity--high complexity, medium complexity, and low complexity--in a hypothetical cancer genetic counseling session. Study participants were asked to imagine themselves as the genetic counseling client as they watched a set of videos in one of the complexity levels. Demographic information and personal characteristics were collected and survey measures and open-ended questions were used to capture outcomes from experiencing the video cancer genetic counseling session.

Aim 1: To assess how characteristics of information provision and complexity affect analogue clients' affective and cognitive outcomes.

Sub Aim 1-1: To measure effects of information provision style on emotional response and satisfaction.

Sub Aim 1-2: To measure effects of information provision style on post-interaction knowledge.

Sub Aim 1-3: To capture effects of information provision style on decisional outcomes (test decision and decisional conflict).

Sub Aim 1-4: To compare participants' self-reported engagement between three different genetic counselor communication styles.

- ***Hypotheses for Aim 1:*** Broadly, we hypothesize that the low complexity communication will perform the best across all outcomes. Based on principles of adult learning theory and oral literacy demand, including elements of interactivity and plain language use, we have reason to believe that lower communication complexity will improve outcomes over high complexity communication.

Aim 2: To examine the association between clients' personal characteristics' (demographics, family history, genetic literacy, and patient-provider orientation) and outcome measures.

- ***Hypotheses for Aim 2:*** We hypothesize that personal characteristics will be associated with genetic counseling outcome measures.

(1) We predict genetic literacy will be inversely associated with satisfaction, perceived respect, and knowledge.

(2) We predict a patient-provider orientation will be inversely associated with satisfaction and respect such that those who expect a more patient-centered interaction will have lower levels of satisfaction and perceived respect.

(3) We predict perceived personal risk for cancer will be positively associated with negative emotional response.

Sub Aim 2-1: To examine moderating effects of personal characteristics on links between information characteristics and analogue client outcomes.

- ***Hypotheses 2-1:*** We predict genetic literacy, patient-provider orientation,

and personal perceived risk for cancer will moderate the effects of communication complexity on study outcomes.

CONCEPTUAL FRAMEWORK

Conceptualization of this study and the examination of communication of genetic information draws upon adult learning theory principles and the oral literacy demand framework. In order for adults to learn, they need to feel that the information is personally relevant to them, and they need to be actively engaged in the learning process (Knowles, 2011). Though there are numerous individual theories, broadly, adult learning theories emphasize the importance of personal relevance, active engagement in learning, using experience to learn, and focusing on a problem (Knowles, 2011). Consideration of the oral literacy demand framework goes beyond the learner's process needs and describes characteristics of the provider's communication (Roter et al., 2007). Specifically, the four major components of oral literacy demand include the use of medical jargon and technical terminology, language complexity, interactivity, and content density. The higher the oral literacy demand, the more difficult it may be for individuals, particularly individuals with lower genetics or health literacy or non-native speakers of English, to effectively learn and find personal meaning in the information that is given to them by the provider. Given that genetic counseling has been shown to be a provider-dominated and disease-centric conversation, theory would suggest that tailoring the way information is communicated could change client engagement in the session and in their healthcare, and could potentially impact immediate emotional, decisional, satisfaction, and information recall outcomes. More broadly, improving clients' ability to understand the key information content through reducing language complexity and increasing engagement in the session could enhance short-term outcomes--including understanding, satisfaction, and trust-- which could also have longer term implications for adaptation,

health behavior, and overall health outcomes (Street et al., 2009). Thus, understanding if and how the complexity of communication impacts client outcomes, and characterizing the moderating effects between personal characteristics and communication complexity on genetic counseling outcomes could help guide evidence-based practice.

In our conceptual framework, we have incorporated clients' personal characteristics to represent clients' factors that may affect how they react to a genetic counseling session . As described previously, genetic counselors' personal characteristics are also hypothesized to affect the interaction. However, our study design holds the genetic counselor constant, as the provider's personal characteristics are not the focus of this study. Within the clinical encounter, communication of genetics information makes up a large component of the time and focus of the genetic counseling session. Principles of oral literacy demand and adult learning theories can describe elements of the process of genetic counseling communication. In our case, these are experimentally manipulated. In this framework, within the clinical encounter, patient engagement is affected by the provider's communication of information, and the encounter leads to decisional outcomes (i.e. decision to have genetic testing, decisional conflict) as well as affective and cognitive outcomes (for example, satisfaction, emotional response, and knowledge recall). While our study aims to capture post-session outcomes measured immediately following genetic counseling, longer term secondary health outcomes may be affected by the clinical encounter and the decisions, feelings, and thoughts that occur during and afterwards.

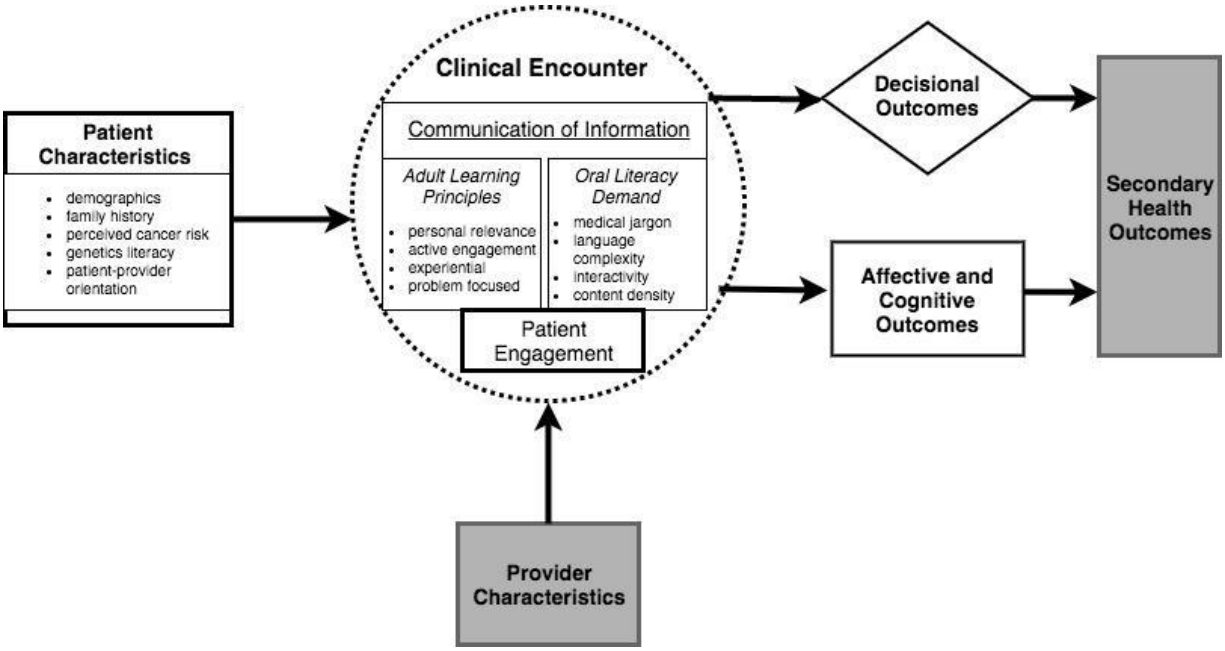


Figure 1. Conceptual Framework

Patients come to the clinical encounter with varying personal characteristics. Providers likewise have personal characteristics that affect the clinical encounter. Within the clinical encounter, communication of genetics information, characterized by factors related to adult learning principles and oral literacy demand, affects patient engagement with the information, leading to decisional, affective, and cognitive outcomes. The communication in the clinical encounter and its short-term outcomes may impact long-term secondary health outcomes.

METHODS

Study Design Overview

The study design was a mixed methods experimental design using a hypothetical video cancer genetic counseling scenario through an online survey platform (Qualtrics). The study was deemed by the NIH Office of Human Subjects Research Protections to be exempt from a full IRB review process, as no personally identifiable information was linked to study data, retained, or shared. Participants were recruited from two adult volunteer cohorts, the NIH Clinical Research Volunteer Program and ResearchMatch. Ostensibly "healthy" (without a personal cancer history) volunteers were targeted for this study due to the hypothetical nature of the study. The hypothetical scenario involved asking the participant to imagine that she was a woman referred for genetic counseling after her sister's recent cancer diagnosis to discuss personal risk and genetic testing options available. Inclusion and exclusion criteria were chosen to increase the likelihood that the hypothetical scenario would feel real without being so similar as to make it likely that a participant would view the research exercise as a replacement for receiving personal genetic counseling. Inclusion criteria were English speaking adult women with a family history of at least one family member who has had cancer (excluding basal cell skin cancer), but with no personal history of cancer (excluding basal cell carcinoma), as well as no previous experience meeting with a genetic counselor. Women reporting a sister with breast cancer were excluded from study to remove the possibility of conflating the study with clinical care and to attempt to avoid more extreme emotional responses in the absence of an in-person genetic counselor. The population was limited to English-

speakers due to validation of survey instruments in English, and the interactive nature of the online web-based tool being developed in English.

Participants were emailed an invitation to participate in the study if they met the inclusion criteria, and were directed to follow the link to an online Qualtrics platform if they were interested in participating. The participants were presented with an online consent document and then asked if they wished to participate and also asked to verify that they met the inclusion requirements for the study. The platform was self-directed, and participants could proceed at their own pace through collection of demographic information, surveys, watching the genetic counseling videos, post-counseling surveys, and open-ended questions.

Description of Study Participant Populations

Clinical Research Volunteer Program (CRVP) at the National Institutes of Health

The Clinical Research Volunteer Program (CRVP) is comprised of individuals who have contacted the National Institutes of Health (NIH) to give permission to researchers to recruit them for research study participation. These individuals are considered "healthy" volunteers without a known or stated health condition. The individuals in the Clinical Research Volunteer program are generally of higher socioeconomic status than the general population, have proactively volunteered for NIH research, and are thus possibly more willing and engaged in participating in the experimental web-based study design than members of the general public. Due to specific recruitment at the NIH to increase racial diversity for a separate ongoing NIH study

known as ClinSeq, the "A2" ClinSeq cohort, comprised of African Americans, comprises up to 30% of potential research participants in the group.

ResearchMatch

The ResearchMatch cohort is comprised of individuals who have contacted the national ResearchMatch registry to give permission to researchers nation-wide to recruit them for research studies or use their self-reported health data for analysis. These individuals self-report any health information and problems they wish to disclose into the ResearchMatch database. Similar to the CRVP, the participants have higher socioeconomic status than the general population, and over 90% of the participants are white. When recruiting through ResearchMatch, the researcher has the ability to sort participants by specific qualities, and women over 18 who reported no personal history of cancer were selected. The recruitment email then specified the additional inclusion criteria.

Recruitment Procedures

Study participants were recruited through CRVP and ResearchMatch. For the CRVP participants, a CRVP staff member sent recruitment emails to potentially eligible participants inviting them to either contact the researcher directly (first recruitment set) or to follow a direct online link to the study (subsequent recruitment sets) (See Appendix A). For ResearchMatch, the researcher was granted access to the database, and filtered potential participants by the inclusion criteria in order to generate a random list of eligible participants. From that set, the research selected a subset to generate a list of race-matched eligible participants, based on the racial demographics of the CRVP cohort

(which has ~25-30% non-Caucasian participants). Emails were sent through the ResearchMatch system directly to that subset, and recipients selected whether or not they wished to be contacted about participation. From there, the researcher was able to send a direct email with the link to the study.

Pilot Study

Piloting of the survey and the online platform was performed remotely with three NIH CRVP volunteers who met study eligibility criteria. The participants completed the study while on the phone with the researcher, and were asked to speak aloud about any issues (technical or otherwise) they were having or portions that were confusing. At the end of the survey, the researcher asked additional questions about what could be done to improve the study in clarity, ease, and efficiency, as well as how to increase the likelihood of participants completing the entire survey. Average timing of the survey was also recorded in the piloting phase, in order to attempt to keep the completion time between 30-45 minutes. Minor changes were made based on the participant feedback, including wording clarification and the addition of "N/A" to the family history questions.

The Study Instrument

Consent and Human Verification

Consent was obtained electronically through the first web page of the Qualtrics survey (see Appendix B). Description of benefits, potential risks, participation requirements, and contact information of the researchers was provided should the participant have any questions or concerns. In order to prevent fraudulent participation, a human verification reCAPTCHA was used. Additionally, participants were only allowed

to complete the survey once. Participants who did not meet eligibility criteria were diverted from continuing the rest of the survey through built-in screening questions administered after the consent process.

Participant Personal Characteristics

Participant demographic information was collected including: age, race, ethnicity, education, income, marital status, and number of biological children (See Appendix C for full study instrument). Personal family history information was collected to quantify the number of affected individuals and the types of cancers in the family, specifically a family history of breast and/or ovarian cancer and male breast and/or prostate cancer. To further qualify the participant's perception of personal risk for developing cancer, she was asked what she thought about her own risk of developing cancer in the future, with responses ranging from (1) much lower than average to (5) much higher than average. This method of collecting personal perceived risk for cancer has been adapted from work from Rubinstein and colleagues who surveyed 2,505 women about their family histories to examine how disease perceptions for cancer were associated with family history (Rubinstein et al., 2011).

Beyond demographic characteristics and family history, genetic literacy level and patient-provider orientation were collected using validated and widely used measures. Genetic literacy was measured using the Genetic Literacy Comprehension (GLAC) measure adapted from the Rapid Estimate of Adult Literacy in Genetics (REAL-G) short measure to capture genetic literacy in a survey format by combining familiarity of genetics-related words with correctly selecting the appropriate term to use in a sentence, in total of 18 questions (Erby et al., 2008; Hooker et al., 2014). For each individual,

familiarity scores are averaged and added to the number of correctly matched words in the provided sentences, with a possible score range of 0.2-15, with a higher score indicating higher genetic literacy.

Additionally, patient-provider orientation was collected using the Patient-Provider Orientation Scale (PPOS) (Krupat et al., 2000). Patient-provider orientation is a measure of how individuals prefer and expect to interact with their healthcare providers. The scale is comprised of 18 questions, divided into "sharing" and "caring" scales (Krupat et al., 2000). Our version used a 7 point Likert scale from (1) "Strongly Disagree" to (7) "Strongly Agree". Taken together, a higher total mean score is indicative of preference for patient-centered care while a lower mean scores is indicative of a preference for "disease-" or "doctor-" centered care. For the purposes of our study, we collected "sharing," "caring," and the combined patient-provider orientation scores to capture a more robust impression of how participants think and feel a provider should interact with them.

Hypothetical Scenario Description

After collecting participant characteristics, the participants were directed to consider the following hypothetical scenario:

> *"Imagine that you have a sister and that she was recently diagnosed with invasive breast cancer at the age of 39. She suggested that you meet with a genetic counselor about your risk for breast cancer, and an optional genetic test that could be available to you if you were interested. Today, you'll be watching videos that represent what genetic*

counseling sessions might look like, and you'll be asked a series of questions about your thoughts, feelings, and experiences overall after viewing the videos.

The genetic counselor may also ask you questions during the session. While we won't be recording your responses to those questions, in order to enhance the reality of the videos, please respond when the genetic counselor poses a question (out loud or in your head). Please answer the questions as if this were a real situation, but also remember that this in no way reflects your actual personal risk for breast and ovarian cancers."

This particular scenario was chosen because, as awareness of genetic testing expands, having a close family member with early-onset cancer is an increasingly common reason for clients to present to genetic counseling. In addition, a similar scenario was used in the GCVP, providing a model for typical information provision in this context (Erby et al., 2006).

Development of the Simulated Cancer Genetic Counseling Videos

Scripts for the video cancer genetic counseling sessions were developed through a combination of using previously-collected cancer genetic counseling transcripts from the Genetic Counseling Video Project (GCVP), audio recordings from a more recent but as yet unpublished graduate study (Setzer et al., unpublished), the student's (EB) clinical training experience in a cancer genetic counseling clinic, and consulting with two practicing genetic counselors for reality and accuracy in informational content. Transcripts from the GCVP with the highest scores in self-reported similarity to actual

practice were first selected to prioritize reality of practice. Informational points (i.e. risk figures, discussion of genes, inheritance patterns, etc.) as well as wording of explanations of those points were noted. Other aspects of communication, including question asking and checking for understanding (i.e. "Okay?") were also noted. Audio recordings from Setzer's more recent communication study were used to corroborate the informational content as well as to note any changes in focus since the GCVP was conducted (i.e. mention of gene panels beyond *BRCA1* and *BRCA2*, variants of uncertain significance, GINA) (Setzer, unpublished; Roter et al., 2006; Hooker et al., 2017).

A written draft of the informational components of a typical pre-test genetic counseling visit was developed based on these two sources. Scripts were designed to include all of the parts of a typical pre-test genetic counseling session that involved information provision. Family history and medical history information gathering, as well as any personal exploration of clients' values and the personal meaning of information were excluded, as they were not considered to be part of information provision. The first script was developed to reflect the highest communication complexity, based on what was noted in the GCVP transcripts, and the other two scripts were developed afterwards.

In order to create three distinct scripts of increasing levels of complexity, quantitative measures of language complexity and aspects of oral literacy and adult learning principles were modified. Elements including Flesch-Kincaid reading level, medical jargon, words per sentence, percentage of passive sentences, "you" statements, open-ended questions, and teach-back utilization were altered. Medical jargon use was approximated using a method recently developed by Erby and colleagues that quantifies

the use of more than 4000 pre-identified medical jargon terms (Erby et al, unpublished). The summary of the differences between the three levels is summarized in Table 1.

The high complexity script was designed to be highest in language complexity, lowest in interactivity, with minimal checks for understanding, and no teach back. The low complexity was designed to have lowest language complexity, highest interactivity, and more checks for understanding including teach back. The medium complexity was designed to be intermediate between the two, with language complexity levels between the other two levels, but with interactivity and teach back similar to the low complexity. Compared to the high complexity, the medium complexity used more plain language but the same amount of informational details, and the low complexity had both more plain language and fewer informational details, though the same general factual concepts were included in all three complexities. Even within the high complexity videos, great care was taken to ensure that language use was similar to sessions included within the GCVP simulation study of routine care.

To approximate interactivity, each arm progressed as a series of consecutive 8-17 short videos (4 seconds to ~8 minutes in length) during which the genetic counselor in the video would talk and then pause for the client to consider what her response would have been had she been sitting in a real session before moving on to the next video in the series. The shortest video clips were clips of the genetic counselor prompting the participant with a question, and the longer clips contained communication of information. There were more videos in the medium and low complexity levels (17 each compared to 8 in the high level), approximating more interactivity with the same basic informational concepts included. The medium and low complexity levels also included additional open

ended questions to prompt engagement beyond answering "yes" or "no". The average time and total time of these videos was also shorter than the "High" complexity videos, allowing more time and opportunities for the participant to engage verbally or mentally. Sessions with more technical information and medical jargon have been shown to be longer in the GCVP (Roter et al., 2007).

After the three scripts were developed, a practicing genetic counselor edited the scripts for clarity and language. Following those revisions, an additional practicing cancer genetic counselor was then consulted to review the reality, validity, and accuracy of the information in the scripts, and a third practicing genetic counselor edited the scripts for clarity and language before finalizing the scripts (refer to Appendix D for full video scripts). To maximize reality of the videos, a practicing genetic counselor comfortable and familiar with genetics concepts served as the genetic counselor in all videos for all three communication complexity levels.

Randomization

The Qualtrics online study platform automatically randomly assigned each participant to watch one set of genetic counseling videos (High, Medium, or Low complexity), balancing to maintain equal numbers across the three groups.

Table 1. Video Dialogue Script Complexity Measures

Complexity Measure	High	Medium	Low
Flesch-Kincaid Reading Level	10.2	8.0	7.2
Medical Jargon	466 uses	344 uses	200 uses
Turn Taking	7	17	17
Total Words	3666	3196	2742
Words/sentence	19.9	16.4	14.9
Passive Sentences	13.6%	12.8%	11.6%
"You" Statements	132	148	142
Open-Ended Questions	3	11	15
Teach-Back Utilized	No	Yes	Yes
Number of Videos	8	17	17
Range in Video Length (Avg)	6s-7m46 (2m43s)	5s-2m59s (1m5s)	4s-2m38s (37s)
Total Video Length of all videos	21 min	18 min	12 min

Communication complexity level was varied across three levels (High, Medium, and Low) in video clips of a genetic counselor speaking to the hypothetical patients. Quantitative measures of oral literacy demand and language complexity were altered to reflect differences across the three levels.

Table 2. Length of Video Clips

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
H	30s	3m	3m 17s	2m 13s	7m 46s	2m 39s	2m 17s	6s									
M	23s	5s	52s	1m 37s	46s	1m 44s	11s	1m 12s	2m 43s	2m 59s	1m 31s	1m 12s	52s	8s	59s	1m 7s	7s
L	24s	4s	54s	6s	32s	52s	6s	56s	1m 19s	2m 38s	1m 27s	12s	42s	52s	59s	26s	6s

H: High complexity
M: Medium Complexity
L: Low Complexity

The amount of time in each video clip for each complexity level is summarized. The study participant was prompted with a question or thought at the end of each clip, representing interactivity and turn taking. Content in each respective video clip number (e.g. #5 in high vs. #5 in medium) is not assumed to be the same across the three levels.

Outcome Measures and Scales

(1) Genetic Test Decision

Following the video genetic counseling session, participants were prompted with the question, "*If you were the client seeing this genetic counselor, would you want to have genetic testing today?*" and asked to select, "*Yes*," "*No,*" or "*Maybe*" before proceeding to the remainder of the survey.

(2) Emotional Response

In order to gather the emotional response from the video genetic counseling experience, a scale which has been validated and utilized in the GCVP and previous genetic counseling research was used (Roter et al., 2006; Butrick et al., 2011). This scale asks the survey taker to select how strongly they are feeling each of the following seven emotions: fear, ease of mind, confusion, confidence, frustration, and difference from others on a 7-point Likert scale from None (1) to Very Much (7). Scores for positive emotions (ease of mind and confidence) and negative emotions (fear, confusion, frustration, different from others) are totaled.

(3) Decisional Conflict

Decisional conflict is an outcome measure which goes beyond positive and negative emotional reactions to capture specific feelings and thoughts about the decision individuals made (O'Connor, 1995). The decisional conflict scale has been used broadly in medical and genetic counseling settings, including in cancer settings, to quantify how conflicted individuals feel about health decisions they have made (or hypothetically made) (Katapodi et al., 2011). The scale is divided into three subscales including: decision uncertainty, factors contributing to uncertainty, and perceived efficacy in

decision making. The scale is a 16 question 5-point Likert scale from "Strongly Agree" (1) to "Strongly Disagree" (5), with a higher score indicating higher decisional conflict. Negative questions are reverse scored so that all questions are in the affirmative, and an average score can be derived from all 16 questions.

(4) Perceived Respect from the Provider

Participants were asked to rate to what degree they felt respected by the video genetic counselor ("*My genetic counselor has a great deal of respect for me*") on a scale from (1) Strongly Agree to (5) Strongly Disagree. This method of collecting perceived respect has been used in similar studies (Butrick et al., 2011).

(5) Genetic Counseling Satisfaction

Previous studies have shown that patients are generally satisfied with genetic counseling (Veach et al., 1999; Shiloh et al., 1990), but we aimed to detect a difference in satisfaction between the three communication complexity levels and/or to detect differences between participants based on specific personal characteristics. Satisfaction with the genetic counseling session was gathered using the validated Genetic Counseling Satisfaction Scale (GCSS) widely used in genetic counseling, and validated in cancer genetic counseling specifically, to measure satisfaction outcomes of genetic counseling (Tercyak et al., 2001; DeMarco et al., 2004).

(6) Knowledge

In order to measure post-counseling knowledge, participants were given 10 true or false questions to answer about cancer and genetics. The questions were drawn from a cancer knowledge recall test, a validated scale to measure knowledge based on main facts typically conveyed in cancer genetic counseling, and wording was altered to reflect

language in the video scripts (Lerman et al., 1997). All factual points on the test were included in each set of the videos, regardless of complexity level. Pre-test knowledge was not evaluated so as not to prime the participants to attend to specific pieces of information.

(7) Verisimilitude and Similarity to Other Health Care Received

The video genetic counseling sessions and hypothetical scenario may have detracted from verisimilitude for the participants, and we wanted to see if there were any differences across complexity levels and to generally characterize the experience overall. We wanted to understand how it felt for the participants to watch the videos and place themselves in the hypothetical scenario, so they were asked:

"*How easy was it for you to take on the patient role when viewing the video genetic counselor?" (1- Very difficult to 4- Very easy)*

"How real did the genetic counselor in the video seem?" (1- Not at all real, to 4- Very real)

"How similar was the genetic counselor to health care you have received in the past?" (1- Not at all similar, to 4- Very similar).

(8) Open-Ended Questions

Following the videos, participants were asked a number of open-ended questions to gather qualitative data about their experience as the client. They were also asked questions including what they learned, what information they found most helpful to their decision, what information they found most confusing, what else they would have liked to say or ask, what else they would have liked to learn, if there was anything they wished the researchers to know. These qualitative data were intended to help provide context for

the quantitative results as well as offer a more nuanced understanding of the participants' experiences.

(9) Self-Reported Engagement

Throughout the video cancer genetic counseling session, the counselor prompted the participant to answer open- and close-ended questions. Participants were asked to verbally or mentally respond to the questions, though no audio or text data was collected. As a rough proxy of engagement, participants were asked to report how often they answered questions: *"When the genetic counselor asked you a question, how often did you answer the question (out loud or in your head)?" (1- Not at all, to 5- All of the time).*

(10) Research Integrity

In order to attempt to filter out the data of participants who did not answer the surveys honestly or to capture those who sped through the survey to get to the end, participants were asked, "*The integrity of our research data is important to us. Have you answered the survey questions honestly? You will be compensated regardless of your answer, and your answer will not be linked to your email address or personal information.*"

(11) Contact Information Collection and Future Contact Preference

At the end of the study, the Qualtrics platform redirected participants to a separate webpage, unlinked to their study data, that asked for an email address and to state a preference for whether they wished to be contacted about the results of the study. Participants were emailed a $10 Amazon electronic gift card after completion of the study.

Sample Size and Power Calculation

The primary aim of the study was to detect significant differences in affective and cognitive outcome measures between the three randomized communication complexity groups (high, medium, and low). A sample size of 260 was calculated to power the study to detect the situation in which differences in communication complexity account for at least 3% of the variance in the affective and cognitive outcomes. When the communication complexity group explains 3% of the variance of the outcomes, and the model explains 10% of the variance, at an alpha level of 0.05, 80% power would have been achieved in the study.

Analysis Plan

This study used a three group experimental design with data collected through an online video and survey instrument tool, Qualtrics. The study was a mixed methods study, and survey responses produced quantitative and qualitative data. STATA Statistical Software was used to analyze the quantitative data, and descriptive analysis was used to determine ranges, means, medians, standard deviations, and frequencies for all variables. Bivariate (Pearson's correlations) and multivariate analyses (multiple linear regressions) were performed to look for correlations and significant associations between variables. To compare outcomes between the three groups, multiple linear regression models were created using backwards stepwise elimination of covariates to detect any statistically significant differences between the three complexity groups, and a chi squared test was used to compare testing decisions across the three groups. The survey data were also analyzed using the same backwards stepwise elimination multivariate

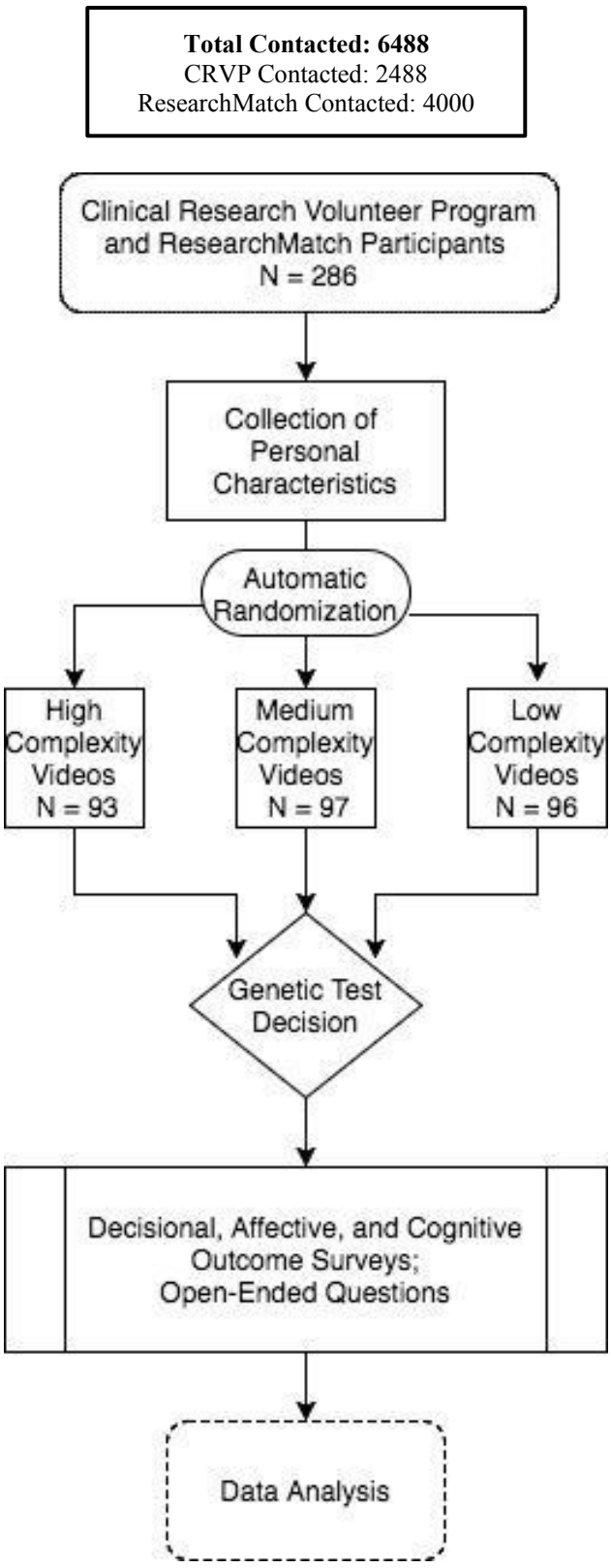
models to examine the relationships of personal participant characteristics (demographic information, genetic literacy, and patient-provider orientation) with each affective and cognitive outcome (satisfaction, emotional response, decisional conflict, perceived respect, knowledge and information recall, ease, reality, and engagement). Interaction effects between complexity and personal characteristics were explored by creating interaction terms in multiple linear regression models using personal characteristic covariates that were found to be statistically significantly associated with outcomes in the original multivariate models. Regression models stratified by complexity level were performed to further characterize effect modification in instances where interaction was detected. Statistical significance for the study was be assumed to be $p < 0.05$.

Table 3. Study Independent and Dependent Variables

Independent:	**Dependent:**
● Demographic Factors: ○ *Age (cont.)* ○ *Race (dichot.)* ○ *Ethnicity (dichot.)* ○ *Marital Status (cat.)* ○ *Number of Biological Children (cont.)* ○ *Education (cont.)* ○ *Income (cont.)* ● Reported Family History of Cancer (dichot.) ● Perceived Personal Risk of Cancer (cont.) ● Genetic Literacy (GLAC) (cont.) ● Patient-Provider Orientation (PPOS) (cont.)	● Genetic Test Decision (cat.) ● Emotional Response (cont) ● Decisional Conflict (cont.) ● Cancer Knowledge (cont.) ● Satisfaction in GC (cont.) ● Perceived Respect from GC (cont.) ● Verisimilitude (Ease of Imagining Self as Client, Reality of GC) (cont.) ● Perceived Similarity of Video GC to other Healthcare Experiences (cont.) ● Self-reported Engagement in GC Session (cont.)

cont.	treated as continuous variable
cat.	treated as categorical variable
dichot.	treated as dichotomous variable

Figure 2. Study Design Flow



RESULTS

Recruitment and Completion Rates

Study recruitment began with the CRVP. 263 eligible individuals who had joined the CRVP within the last year were randomly selected from the participant database, and were emailed an invitation to contact the researcher for more information about completing the study. Around 50 participants replied that they would be interested in participating. Three of those individuals participated in the pilot study, and the remaining were later sent a link to the Qualtrics study to participate. Following the first recruitment emails, additional emails were sent to eligible CRVP who had joined the CRVP in the last four years, in batches of 500-1000. A total of 2,488 CRVP participants were invited.

In order to boost study participant numbers, ResearchMatch was used as an additional recruitment method. Lists of race-matched (~25-30% non-Caucasian) eligible participants were generated from the database of over 120,000 total participants. Using the internal database, lists containing a total of 6000 Caucasian women were generated and from those lists, a total of 3,000 were randomly selected to be recruited. In the same way, multiple lists containing a total of 3,000 non-Caucasian women were generated, and a total of 1,000 were randomly selected to be recruited. In total, 4,000 women participants were contacted with the option to learn more about the study. From the 4,000 contacted, 215 agreed to be contacted further about the study, and those individuals were sent a link to the Qualtrics survey.

From the 6,488 individuals that were invited to participate from both cohorts, 2,703 were ultimately given the link to the survey. Of those 2,703, there were a total of 503 attempts at the study, and 305 completed studies, and 15 who indicated that they

were not eligible to complete in the screening question, resulting in about 60% completion from those who were eligible that began the survey. The completion rate from all that were invited to participate was 4.7%, and the completion rate from those that were given the study link was 11.3%. Of the 183 that did not fully complete the study, 46 (23%) did not proceed past the consent page and 81 (44%) quit while taking the personal characteristic surveys before watching the genetic counseling videos. Overall, 43 (24%) quit while watching the videos (18 in high, 15 in medium, 10 in low), 4 (2%) quit immediately after making a genetic test decision (2 in high, 2 in medium), and 9 (5%) quit while taking the post-counseling surveys (7 in medium, 2 in low). Table 4 summarizes completion rates by complexity level, and shows that the majority of those that quit before completion quit before watching the genetic counseling videos (67%).

Of the total 305 completed at the time that the study was closed, 9 responded "No" to the question asking if they had answered the questions honestly and were removed from the dataset. Upon examination answers from those 9 participants demonstrated several potential problems including: incomplete responses, responses that demonstrated a predictable pattern, and multiple surveys that were taken around similar time points. For the purposes of our study, data were analyzed from the first 286 participants that completed the survey and self-reported that they had been honest in their answers, as the remaining 19 surveys were received at a later date.

Among the 286 participants included in the analysis, there was very few missing data. However, 34 participants did not report their age. In order to analyze the data from as many participants as possible, imputation using the median age of 38.5 was used to fill missing age data points. Data tables include the number of participants (N) that answered

each measure or survey question. Missing data for other independent or dependent variables besides age were dropped from analysis for that covariate, as most measures did not have more than two or three missing data points.

Participant Personal Characteristics

Demographics

The sociodemographic characteristics of the study population are summarized in Table 5, and the number of included data points are noted. The participants ranged in age from 19 to 78, with a mean of 41.62, and a median of 38.50. The majority of participants self-reported as Caucasian (69.7%) and non-Latina (93%). For the purposes of our analysis, race was dichotomized into Caucasian and non-Caucasian individuals due to the relatively low proportion of individuals in non-Caucasian racial groups. As expected, the population was highly educated, with the majority having a college degree or above (80%), and more than 45% reporting a graduate degree. The largest proportion of individuals fell into the income category of making more than $100,000 per year (30.77%), but income was spread across all levels. 45.80% of the participants were single, 36.36% were married, 11.54% were divorced, 2.45% were widowed, and the remaining 3.50% stated "Other," with self-reported qualifiers such as "separated," "cohabiting," and "domestic partners." The average number of biological children the participants had was 0.90, rounded to 1 child, with a range from zero to five. Chi squared (χ^2) tests were used to detect significant differences between the high, medium, and low complexity groups for categorical and dichotomous variables, and ANOVA was used to detect significant differences

were found across the three complexity groups for any of the personal characteristics (*p*-values reported in Table 5).

Table 4. Summary of Incomplete Surveys

Quitting Time Point	**Number of participants that quit the study (%)**			**Total Quit = 183**
Prior to Consent	46 (23%)			
Pre-video Surveys	81 (44%)			
	High Complexity	**Medium Complexity**	**Low Complexity**	**Combined**
During Videos	18	15	10	43 (24%)
Immediately After Videos	2	2	0	4 (2%)
Post-video surveys	0	7	2	9 (5%)

The number of participants that quit the survey before completion are summarized, including the time point within the survey at which they quit. The majority of potential participants quit the study prior to consenting to the study or while taking the pre-video demographic and personal characteristic surveys.

Table 5. Participant Demographics

		High Complexity	**Medium Complexity**	**Low Complexity**	**Combined**	**ANOVA or χ^2 *p*-value**
Age		*N=84*	*N=84*	*N=84*	*N=252*	*p=0.8733 (ANOVA)*
	Average Range	42.14 21-77	40.96 19-78	41.75 20-71	41.62 21-78	
Race		*N=93*	*N=97*	*N=96*	*N=286*	*p=0.938* (χ^2)
	Caucasian	66 (70.97%)	67 (69.07%)	66 (68.75%)	199 (69.6%)	
	Non-Caucasian	27 (29.03%)	30 (30.93%)	30 (31.25%)	85 (30.4%)	
Non-Caucasian Race in Detail		*N=93*	*N=97*	*N=96*	*N=286*	*p=0.279* (χ^2)
	African American	18 (19.35%)	14 (14.43%)	21 (21.88%)	53 (18.5%)	
	Asian or Pacific Islander	4 (4.30%)	5 (5.15%)	3 (3.12%)	12 (4.2%)	
	American Indian or Alaska Native	1 (1.08%)	0 (0%)	0 (0%)	1 (0.35%)	
	Other	4 (4.30%)	5 (5.15%)	1 (1.04%)	10 (3.5%)	
	Identify as more than one	0 (0%)	6 (6.19%)	5 (5.21%)	11 (3.8%)	
Ethnicity		*N=92*	*N=96*	*N=95*	*N=283*	*p=0.188* (χ^2)
	Hispanic or Latina	5 (5.43%)	9 (9.38%)	3 (3.16%)	20 (7%)	
	Non-Hispanic or Latina	87 (94.57%)	87 (90.62%)	92 (96.48%)	266 (93%)	

A χ^2 test was used to identify differences between the High, Medium, and Low Complexity groups.

Table 5 cont. Participant Demographics continued

		High Complexity	**Medium Complexity**	**Low Complexity**	**Combined**	**ANOVA or χ^2 *p*-value**
Education		*N=93*	*N=97*	*N=96*	*N=286*	*p=0.451* (*ANOVA*)
	Less than High School	0 (0%)	0 (0%)	0 (0%)	0 (0%)	
	High school graduate (or equivalent)	5 (5.38%)	2 (2.06%)	4 (4.17%)	11 (3.85%)	
	Some College, no degree	10 (10.75%)	14 (14.43%)	8 (8.33%)	32 (11.19%)	
	Associate's degree	4 (4.30%)	5 (5.15%)	5 (5.21%)	14 (4.90%)	
	Bachelor's degree	36 (38.71%)	34 (35.05%)	28 (29.17%)	98 (34.27%)	
	Graduate or Professional degree	38 (40.86%)	42 (43.30%)	51 (53.12%)	131 (45.80%)	
Annual Household Income		*N=93*	*N=97*	*N=96*	*N=286*	*p=0.7124 (ANOVA)*
	<$25,000	12 (12.90%)	8 (8.25%)	12 (12.50%)	32 (11.19%)	
	$25-50,000	15 (16.13%)	25 (25.77%)	17 (17.71%)	57 (19.93%)	
	$50-75,000	25 (26.88%)	16 (16.49%)	20 (20.83%)	61 (21.33%)	
	$75-100,000	18 (19.35%)	13 (13.40%)	17 (17.71%)	48 (16.87%)	
	>$100,000	23 (24.73%)	35 (36.08%)	30 (31.25%)	88 (30.77)	

A χ^2 test or ANOVA was used to identify differences between the High, Medium, and Low Complexity groups.

Table 5 cont. Participant Demographics continued

		High Complexity	**Medium Complexity**	**Low Complexity**	**Combined**	**ANOVA or χ^2 *p*-value**
Marital Status		*N=92*	*N=97*	*N=96*	*N=285*	*p=0.618* (χ^2)
	Single	41 (44.57%)	45 (46.39%)	45 (46.88%)	131 (45.80%)	
	Married	37 (40.22%)	32 (32.99%)	35 (36.46%)	104 (36.36%)	
	Divorced	7 (7.61%)	14 (14.43%)	12 (12.50%)	33 (11.54%)	
	Widowed	4 (4.35%)	1 (1.03%)	2 (2.08%)	7 (2.45%)	
	Other	3 (3.26%)	5 (5.15%)	2 (2.08%)	10 (3.50%)	
Number of biological children		*N=92*	*N=97*	*N=96*	*N=285*	*p=0.6708 (ANOVA)*
	Average Range SD	0.97 0-4 1.24	0.92 0-5 1.30	0.81 0-4 1.16	0.90 0-5 1	

A χ^2 test or ANOVA was used to identify differences between the High, Medium, and Low Complexity groups.

Family History of Cancer and Perceived Personal Risk of Cancer (Tables 6 and 7)

A summary of the self-reported family histories of cancer are described in Table 6. As per inclusion criteria, all participants had a family history of cancer, and reported family histories of individuals with cancer varied across the participants, with some having first degree relatives with cancer and others having more distant relatives with cancer. For the purposes of analysis, family history was dichotomized into individuals who had at least one first degree relative with breast (male or female), ovarian, and/or prostate cancer and those who did not. 69 participants (24%) had at least one first degree relative with breast, ovarian, and/or prostate cancer (22 participants in high, 24 in medium, and 23 in low complexity). Regarding perceived cancer risk prior to watching the videos, participants generally perceived themselves to be between "lower risk than average" and "about the same as average," with an average perceived risk of 2.80 on a scale from 1 (much lower than average) to 5 (much higher than average). ANOVA found no significant differences between complexity groups for dichotomized family history or perceived personal cancer risk (Table 7).

Table 6. Family History

	Cancer Type	**High Complexity**	**Medium Complexity**	**Low Complexity**	**Combined**	**χ^2 *p*-value**
At least one 1st degree relative		*N=93*	*N=97*	*N=96*	*N=286*	*p=0.984*
	Breast, Ovarian, and/or Prostate	22 (23.%)7	24 (24.7%)	23 (24.0%)	69 (24.1%)	
1st degree female relative						
	Breast and/or Ovarian	15 (16.1%)	15 (15.5%)	15 (15.6%)	45 (15.7%)	
	Other	22 (23.7%)	20 (20.6%)	30 (31.3%)	72 (25.2%)	
1st degree male relative						
	Male Breast	2 (2.2%)	1 (1.0%)	1 (1.0%)	4 (1.4%)	
	Prostate	7 (7.5%)	12 (12.4%)	10 (10.4%)	29 (10.1%)	
	Other	26 (28%)	21 (21.6%)	27 (28.1%)	74 (25.9%)	
2nd degree or higher female relative						
	Breast and/or Ovarian	45 (48.4%)	50 (51.5%)	48 (50.0%)	143 (48.3%)	
	Other	48 (51.6%)	48 (49.5%)	42 (43.8%)	138 (48.3%)	
2nd degree male relative						
	Male Breast	3 (3.2%)	6 (6.2%)	0 (0%)	9 (3.1%)	
	Prostate	16 (17.2%)	14 (14.4%)	24 (25.0%)	54 (18.9%)	
	Other	43 (46.2%)	52 (53.6%)	40 (41.7%)	135 (47.2%)	

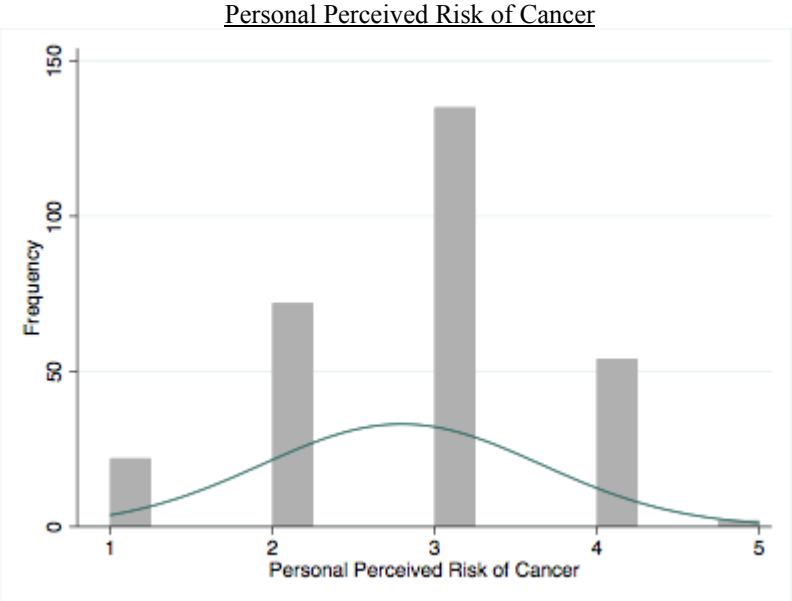
A χ^2 test was used to identify differences between the High, Medium, and Low Complexity groups for having at least one 1st degree relative with breast, ovarian, and/or prostate cancer. This was the dichotomous variable was the covariate approximating family history used in multivariate analyses.

Table 7. Perceived Personal Cancer Risk Scores Summary

	High Complexity	**Medium Complexity**	**Low Complexity**	**Combined**	**ANOVA *p*-value**
	N=93	*N=97*	*N=96*	*N=286*	*p=0.242*
Avg personal risk perception (SD) Range: 1-5	2.88 (0.88) 1-5	2.68 (0.80) 1-4	2.83 (0.90) 1-5	2.80 (0.86) 1-5	

A summary of perceived personal cancer risk scares are summarized by complexity level. ANOVA was used to identify differences between the High, Medium, and Low Complexity groups. No significant difference between groups was found.

Figure 3. Frequency Distribution of Perceived Personal Risk of Cancer



Distribution of perceived personal risk for cancer across all participants (N=286) are shown. Participants tended towards feeling that their risk was "about the same as others" (Average = 2.80 on a scale from 1-5).

Genetic Literacy (Table 8)

As reported in previous studies with the CRVP population, genetic literacy approximated by the GLAC short measure was high, with an average of 14 on a scale from 0.25 (low genetic literacy) to 15 (high genetic literacy). ANOVA found no significant differences between complexity groups for genetic literacy. Frequency distribution of GLAC scores across the study participants are depicted in Figure 4.

Patient-Provider Orientation Scale (Table 9)

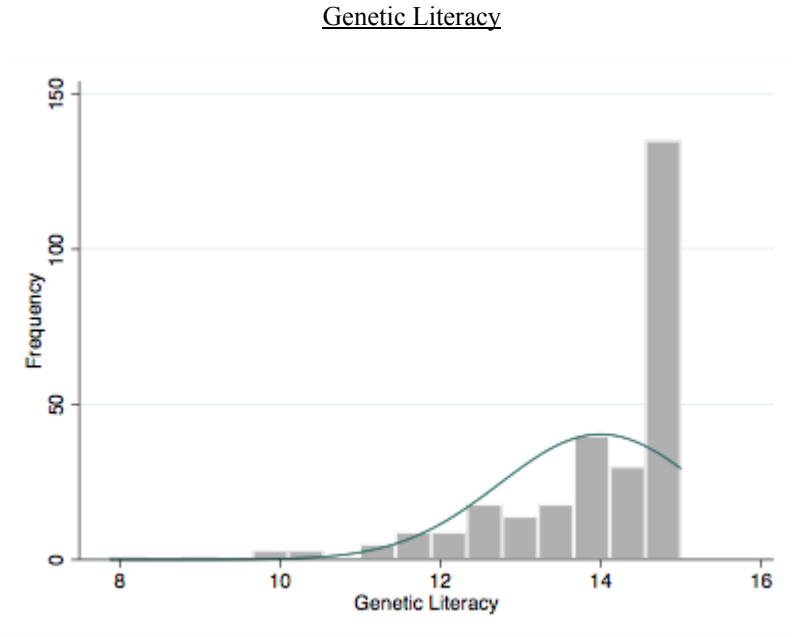
Patient-provider orientation tended towards the patient-centered orientation. The average PPOS score across all participants was 5.24 on a scale from 1 (disease- or doctor-centered) to 7 (patient-centered). The "sharing" subscale of the PPOS, indicating "the extent to which the respondent believes that patients desire information and should be part of the decision-making process," showed an average score of 5.30, indicating a tendency for participants to prefer a sharing model (Krupat et al., 2000). The "caring" subscale, indicating "the extent to which the respondent sees the patient's expectations, feelings, and life circumstances as critical elements in the treatment process," was 5.62, suggesting that the participants prefer a caring model in which their personal values and input are important (Krupat, et al., 2000). ANOVA found no differences between complexity groups for patient-provider orientation.

Table 8. Genetic Literacy Scores (GLAC)

	High Complexity	**Medium Complexity**	**Low Complexity**	**Combined**	**ANOVA *p*-value**
	N=93	*N=97*	*N=96*	*N=286*	*p=0.877*
GLAC score (SD) Range .25-15	14.05 (1.21) 7.88-15	14.00 (1.25) 9.88-15	13.95 (1.32) 9-15	14.00 (1.26) 7.88-15	

Genetic literacy scores are summarized by complexity level. ANOVA was used to identify differences between the High, Medium, and Low Complexity groups. No significant difference between groups was found.

Figure 4. Frequency Distribution of Genetic Literacy (GLAC) Scores



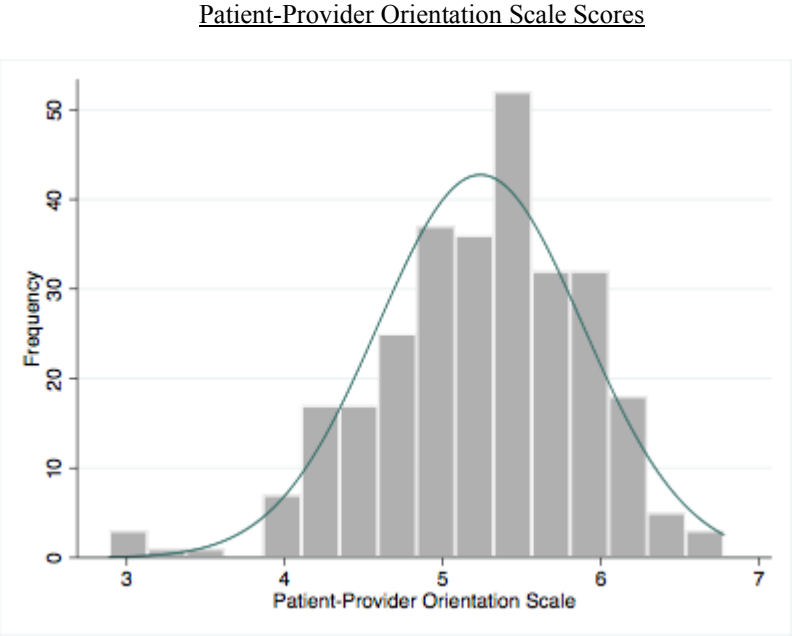
Distribution of the scores on the GLAC scale across all participants (N=286) are shown. Genetic literacy in this participant cohort was high (Average = 14 on a scale of 0.25-15).

Table 9. Patient-Provider Orientation (PPOS) Scores Summary

	High Complexity	**Medium Complexity**	**Low Complexity**	**Combined**	**ANOVA *p*-value**
	N=93	*N=97*	*N=96*	*N=286*	*p=0.475*
PPOS Avg (SD) Range 1-7	5.30 (0.60) 3-6.39	5.18 (0.67) 2.89-6.56	5.23 (0.67) 3.11-6.77	5.24 (0.65) 2.89-6.77	
Sharing Avg (SD) Range 1-7	5.32 (0.79) 2.75-6.67	5.25 (0.85) 2.67-7	5.29 (0.81) 2.67-7	5.30 (0.82) 2.67-7	
Caring Avg (SD) Range 1-7	5.70 (0.56) 3.88-6.78	5.53 (0.61) 3.78-6.89	5.63 (0.59) 4.11-6.89	5.62 (0.59) 3.78-6.89	

Patient-Provider Orientation scores are summarized for each complexity group and all participants combined (N=286). ANOVA was performed to detect significant differences in PPOS between groups; none were found.

Figure 5. Frequency Distribution of Patient-Provider Orientation (PPOS)



Distribution of scores on the PPOS across all participants (N=286) are shown. Participants tended towards patient-centeredness (Average = 5.24 on a scale from 1-7).

Bivariate Analysis

Correlations Between Independent Variables

Pearson's correlations were performed to examine relationships between independent variables (Appendix E). Bivariate analyses were conducted for each personal characteristic variable across all participants. From this analyses we found that older women in our cohort were more likely to be Caucasian. Household income levels increased with age and education. Non-Caucasian individuals were more likely to have lower education levels and lower household income overall. The likelihood of having a higher number of biological children increased with age, and decreased with education level. Personal perceived risk of cancer score tended to be lower in non-Caucasian individuals as well as in individuals with fewer biological children. Interestingly, family history (having at least one first degree relative with breast, ovarian, and/or prostate cancer) was not significantly positively associated with perceived personal risk of cancer. Genetic literacy (GLAC) was positively correlated with education level, and it was lower in non-Caucasian participants. A higher score on the Patient-provider Orientation Scale (PPOS), indicating higher preference for patient-centered care, was correlated with older age, Caucasian race, higher education, higher income, more biological children, and higher GLAC scores.

Correlations Between Predictors and Outcomes

Bivariate analyses were also conducted on personal characteristics with measured genetic counseling outcomes. These analyses were done for the entire cohort as a single group, as well as stratified by complexity level (high, medium, low). Summary tables are presented in Appendix E. These bivariate analyses were also performed stratified by

complexity level. Differences between the three groups are highlighted in Appendix E, showing which personal characteristics were associated with each outcome, and their respective correlation coefficients indicating the strength and direction of the correlation.

Multivariate Models

AIM 1: *Communication Complexity Level and Genetic Counseling Outcomes*

The purpose of Aim 1 was to assess how the complexity level of genetics information communication affected clients' affective and cognitive outcomes. Our hypotheses were that there would be significant differences between some of the affective and cognitive outcomes across the three complexity level groups, with more favorable outcomes for the low complexity group. Tests of skewness and kurtosis were performed on all outcome variables, and residual plots were constructed from their respective multiple linear regression models to capture normality of each outcome. Though a few of the outcomes had some mild skewing or kurtosis, all of the residual plots of the multiple linear regression models showed random patterns, errors were centered around zero, and there were no signs of unbalanced, heteroscedastic, or non-linear trends.

Chi-squared tests were used to compare categorical outcomes (test decision) between the three complexity levels. Multiple linear regression (MLR) models were constructed for each continuous outcome (decisional conflict, positive and negative emotions, satisfaction, perceived respect, knowledge, and verisimilitude) in a stepwise, backwards elimination fashion. These models initially contained all personal characteristics (age, dichotomized race, education, income, number of biological children, marital status, dichotomized family history, perceived personal risk, age,

GLAC, and PPOS) and language complexity level before backwards elimination. The criterion for exclusion was set at p>0.20, with statistical significance at p=0.05. For the multiple linear models, reference groups for categorical variables were: high complexity, Caucasian race, and having no first degree relative with breast, ovarian, or prostate cancer.

Genetic Counseling Outcomes

Decisional Outcomes (Tables 10-11, Figures 6-8)

In examining the decisional outcomes, there was no significant difference in decision to have genetic testing following the video genetic counseling session between the three complexity groups (chi square p=0.909). Across all three groups, 57.34% chose that they would want to do the test ("Yes"), while 27.97% chose that they would not want to ("No"), and the remainder 14.69% indicated they would "Maybe" want the genetic test (Figure 6).

Backwards stepwise elimination of variables in multiple linear regression modeling for decisional conflict showed that the medium complexity remained in the model (p=0.023), though low complexity did not (p=0.5128), with high complexity as the reference group (Table 11). Compared to the high complexity group, the medium complexity group had decisional conflict scores that were 0.167 points higher when controlling for genetic literacy, perceived risk for cancer, income, and race, the other variables in the model (p=0.023). Sensitivity analysis was done by removing three outliers with the highest decisional conflict, and medium complexity remained in the model and the significance level and coefficient were generally unaffected (p=0.025).

Participants' average score on the decisional conflict scale was 2.10, on a scale of 1 (not conflicted) to 5 (highly conflicted), indicating a relatively low level of conflict about the decision to have genetic testing as the analogue client in the hypothetical scenario (Figure 7).

Table 10. Summary of Decisional Outcomes

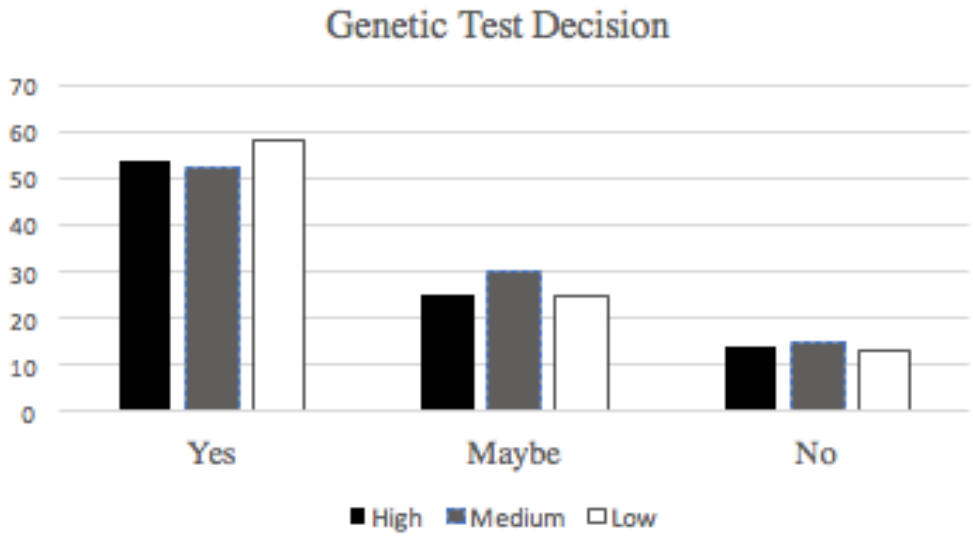
		High Complexity	**Medium Complexity**	**Low Complexity**	**Combined**
Test Decision		*N=93*	*N=97*	*N=96*	*N=286*
	Yes	54 (58.06%)	52 (53.61%)	58 (60.42%)	164 (57.34%)
	Maybe	25 (26.88%)	30 (30.93%)	25 (26.04%)	80 (27.97%)
	No	14 (15.05%)	15 (15.46%)	13 (13.54%)	42 (14.69%)
Decisional Conflict		*N=96*	*N=96*	*N=96*	*N=286*
	Avg Score (SD) Range 1-4	2.03 (0.63) 1-3.69	**2.20*** **(0.59)** **1-4**	2.07 (0.56) 1-3.81	2.10 (0.59) 1-4

* p<0.05, **p<0.01, ***p<0.001

Chi-squared tests were performed to look for differences in categorical outcomes between high, medium, and low complexity.

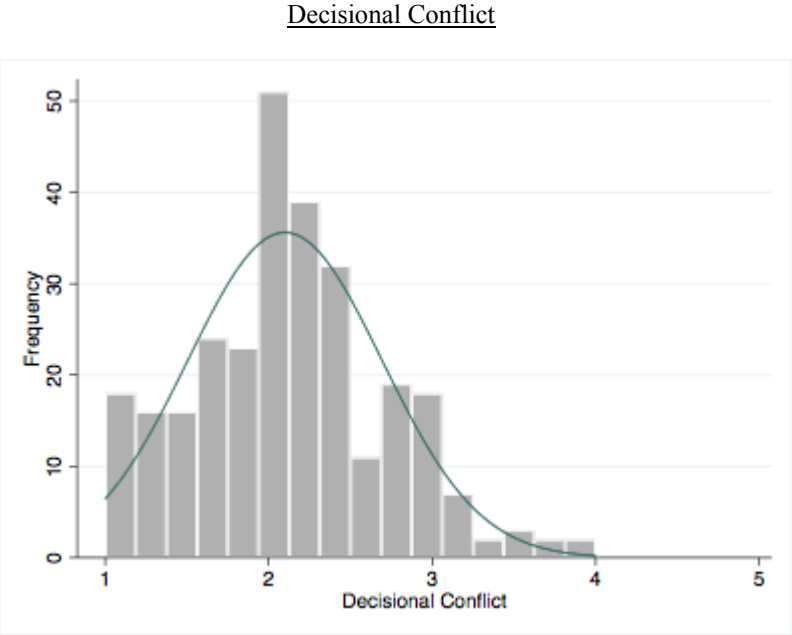
Multiple linear regression models with backwards stepwise elimination were constructed to look for significant differences between high, medium, and low complexity. Significant *p*-values (<0.05) indicate a significant difference from the reference group, high complexity.

Figure 6. Frequencies of Genetic Test Decision



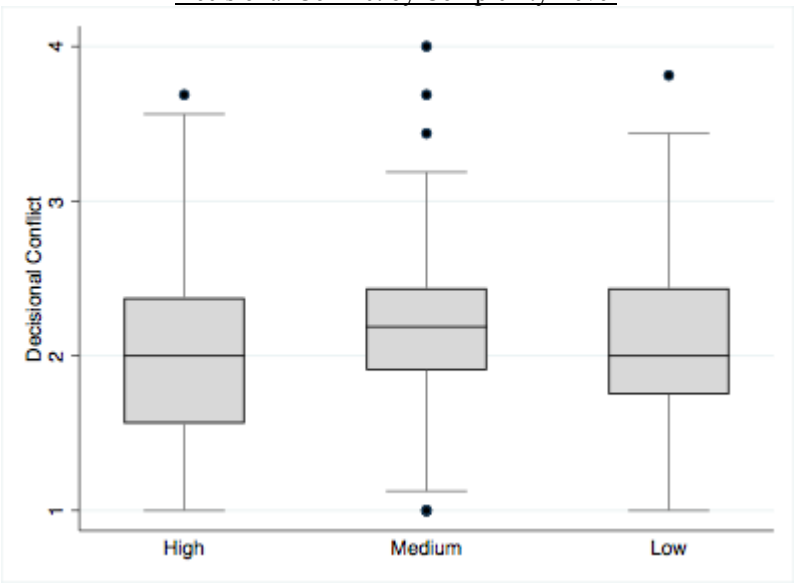
Decision to have genetic testing following the video genetic counseling session are shown by three complexity levels. There was no significant difference in the number of participants who chose testing across the three groups (chi square p=0.909).

Figure 7. Frequency Distribution of Decisional Conflict



Distribution of the scores on the decisional conflict scale across all participants (N=286) are shown. Decisional conflict was slightly positively skewed, but residual plots of the constructed MLR showed no patterns of non-normality.

Figure 8. Boxplot of Decisional Conflict by Complexity Level



Medium complexity remained in the backwards stepwise elimination multiple linear regression of decisional conflict (p=0.023). Sensitivity analysis was done to repeat the regression without the three outliers above the 75% quartile, and the coefficient term remained statistically significant (p=0.025).

Table 11. Regression Model for Decisional Conflict (N=280)

Model $R^2 = 0.0761$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	3.007	0.439	0.000
Medium Complexity	0.167	0.728	0.023
Genetic Literacy (GLAC)	-0.0810	0.0295	0.006
Perceived Personal Risk of Cancer	0.0928	0.0411	0.025
Income	-0.0360	0.0252	0.156
Non-Caucasian Race	0.108	0.0789	0.174

Covariates removed by backwards stepwise elimination (p>.20):

Education	p = 0.8564
Family History	p = 0.8017
Age	p = 0.7312
Marital Status	p = 0.5530
Low Complexity	p = 0.5128
Patient-Provider Orientation	p = 0.3321
Number of Biological Children	p = 0.2857

Emotional Response (Tables 12-20, Figures 9-11)

The backwards stepwise elimination MLR models for positive emotional response showed no significant difference between complexity groups, either as one collapsed outcome (positive emotion) or as distinct emotions (confidence, ease of mind) (medium complexity p=0.648, low complexity p=0.921 compared to the reference high complexity group) (Table 13). However, MLR for negative emotion did detect that participants in the low complexity arm had significantly lower reported levels of negative emotional response as a collapsed variable as well as a significantly lower reported level of confusion as a distinct emotion compared to those in the high complexity group (Table 16, 18). In the low complexity group, negative emotion scores were 0.268 lower than those for the reference group (p=0.042) when controlling for genetic literacy, perceived personal risk for cancer, and race, the other covariates included in the MLR (Table 16). Confusion scores were 0.476 lower in the low complexity group than the reported confusion scores in the high complexity group (p=0.009) when controlling for patient-provider orientation, race, genetic literacy, perceived personal risk for cancer included in the MLR (Table 18). No other significant differences in emotional response between the complexity groups were found (Tables 12-20).

Overall, participants experienced feeling varying degrees and combinations of positive and negative emotions. Taken together, positive emotions were significantly stronger than negative (4.17 vs. 2.66, $p<0.0001$ by t-test). Both types of positive emotions, confidence and ease of mind, had ratings closest to the middle of the scale, indicating that they were felt “somewhat” strongly. Of all negative emotions, fear had the strongest ratings with a score of 3.57. The other negative emotions did not cross the

midlevel (4) (confusion was 2.47, frustration was 2.21, different from others was 2.37), indicating that participants tended to experience those emotions to a lesser degree than "somewhat" but more than "none". Negative emotion was slightly positively skewed, but the residual plots from the MLR were as expected for a normal distribution.

Table 12. Summary of Emotional Response

Emotional Response		**High Complexity** *N=93*	**Medium Complexity** *N=97*	**Low Complexity** *N=96*	**Combined** *N=286*
Average (SD) Range 1-7	Negative	2.75 (1.11) 1-7	2.72 (1.21) 1-7	**2.50* (0.89)** 1-7	2.66 (1.08) 1-7
	Positive	4.12 (1.48) 1-7	4.26 (1.30) 1-7	4.13 (1.32) 1-7	4.17 (1.36) 1-7
	Fear	3.73 (1.44) 1-7	3.43 (1.64) 1-7	3.56 (1.42) 1-7	3.57 (1.5) 1-7
	Ease of Mind	4.15 (1.57) 1-7	4.24 (1.49) 1-7	4.11 (1.46) 1-7	4.17 (1.51) 1-7
	Confusion	2.51 (1.54) 1-7	2.72 (1.63) 1-7	**2.19**** (1.28) 1-6	2.47 (1.51) 1-7
	Confidence	4.10 (1.62) 1-7	4.27 (1.45) 1-7	4.15 (1.52) 1-7	4.17 (1.53) 1-7
	Frustration	2.32 (1.76) 1-7	2.27 (1.56) 1-7	2.05 (1.32) 1-6	2.21 (1.56) 1-7
	Different from Others	2.44 (1.61) 1-7 (N=90)	2.46 (1.72) 1-7 (N=96)	2.20 (1.44) 1-6 (N=95)	2.37 (1.59) 1-7

* $p<0.05$, **$p<0.01$, ***$p<0.001$

A two-sided t-test was performed to detect if negative and positive emotions were significantly different from each other, and mean positive emotion scores were significantly higher than negative ($p=0.0001$).

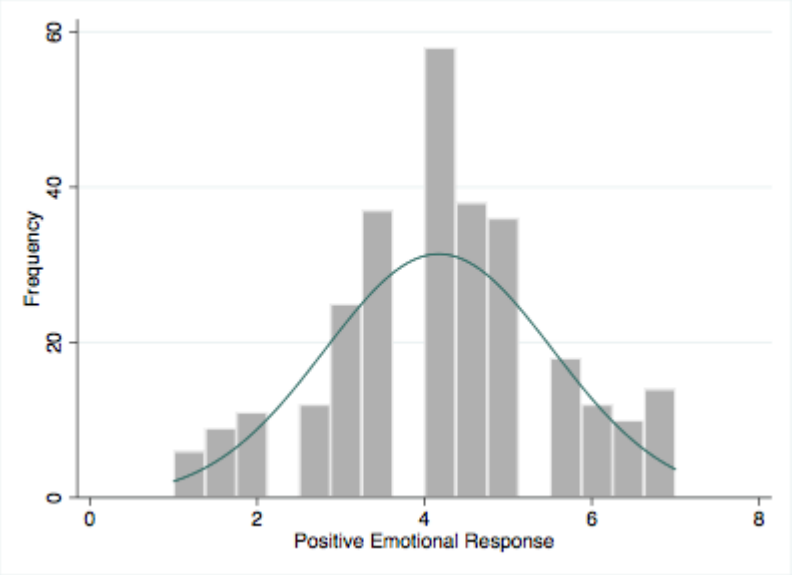
Scores for strength of emotional response by complexity level. Emotional response is shown for positive and negative emotions, as well as each individual emotion that comprises these two broader groups . MLR was performed to detect significant differences between the complexity levels, and the compared to the high complexity level, the low complexity level had lower negative response and lower confusion ($p=0.042$ and $p=0.009$), controlling for the other variables in the MLR for each of those emotional outcomes.

Figure 9. Box Plot of Positive and Negative Emotional Responses

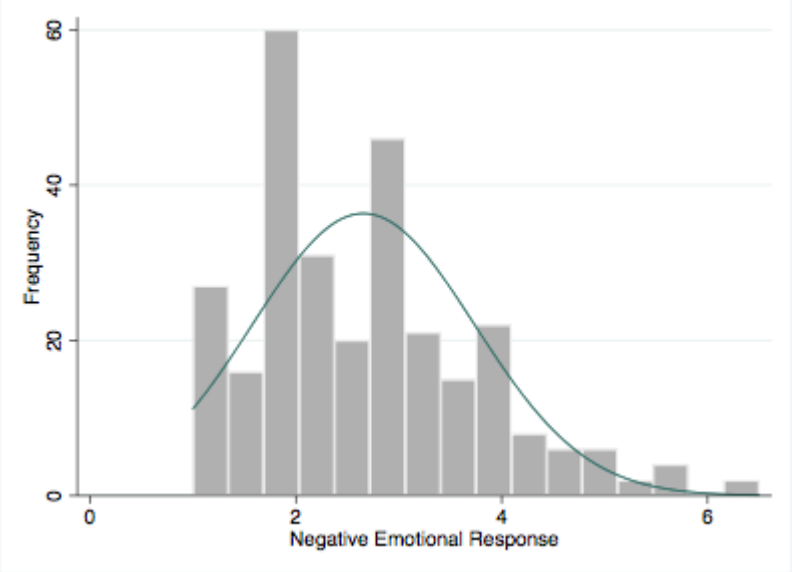
Boxplots of overall positive (N=286, Avg=4.17) and negative (N=286, Avg=2.66) emotional responses are shown. A two-way t-test was done to determine whether the difference in strength of emotion between positive and negative was significant, and positive emotion was found to be significantly higher than negative emotion (p=0.0001)

Figure 10. Frequency Distribution of Positive and Negative Emotional Response Scores

Positive Emotional Response

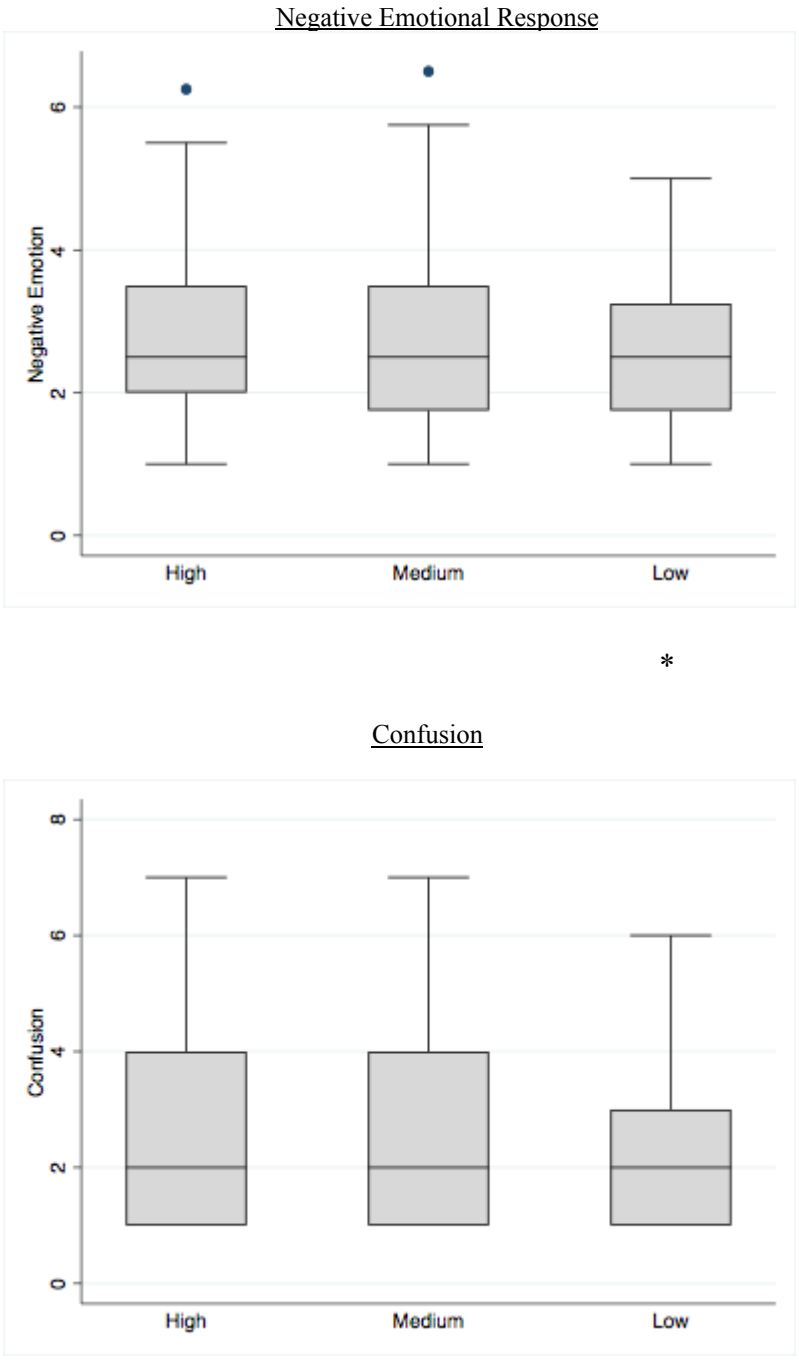


Negative Emotional Response



Distribution of the scores for positive and negative emotional response (N=286) are shown. Negative emotional response was slightly positively skewed, but residual plots of the constructed MLR showed no patterns of non-normality.

Figure 11. Box Plots of Negative and Confusion Emotional Responses



Boxplots of negative and confusion emotional responses are shown by complexity level. MLR was performed to detect significant differences between the complexity levels, and the compared to the high complexity level, the low complexity level had lower negative response and lower confusion ($p=0.042$ and $p=0.009$), controlling for the other variables in the MLR for each of those emotional outcomes.

Table 13. Regression Model for Positive Emotional Response (N=283)

Model $R^2 = 0.0898$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	4.23662	.9815816	0.000
Age	.0153139	.0059774	0.011
Genetic Literacy (GLAC)	.1445069	.0668147	0.031
Patient-Provider Orientation	-.4804467	.1313999	0.000
Education	-.1324871	.0786395	0.093
Family History	.2681855	.1845982	0.147
Household Income	.1191747	.0610284	0.052

Covariates removed by backwards stepwise elimination (p>.20):

Low Complexity	p = 0.9213
Non-Caucasian Race	p = 0.9126
Medium Complexity	p = 0.6475
Marital Status	p = 0.5813
Number of Biological Children	p = 0.3164
Perceived Personal Risk of Cancer	p = 0.3077

Table 14. Regression Model for Ease of Mind (N=283)

Model $R^2 = 0.0803$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	6.342236	.7458306	0.000
Age	.0163227	.0066319	0.014
Education	-.1881505	.0834532	0.025
Patient-Provider Orientation	-.4568312	.1442792	0.002
Family History	.3061405	.2034915	0.134
Income	.1247424	.0677042	0.066

Covariates removed by backwards stepwise elimination (p>.20):

Medium Complexity	p = 0.8941
Marital Status	p = 0.8265
Low Complexity	p = 0.7404
Non-Caucasian Race	p = 0.6461
Perceived Personal Risk of Cancer	p = 0.6338
Genetic Literacy (GLAC)	p = 0.3038
Number of Biological Children	p = 0.2117

Table 15. Regression Model for Confidence (N=283)

Model $R^2 = 0.0806$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	3.399384	1.133223	0.003
Age	.0141509	.0067269	0.036
Genetic Literacy (GLAC)	.201496	.0725232	0.006
Patient-Provider Orientation	-.5097459	.1475133	0.001
Family History	.2837071	.2086699	0.175
Income	.1030085	.0652822	0.116
Perceived Personal Risk of Cancer	-.1341563	.1044163	0.200

Covariates removed by backwards stepwise elimination (p>.20):

Low Complexity	p = 0.9648
Non-Caucasian Race	p = 0.7983
Medium Complexity	p = 0.6042
Number of Biological Children	p = 0.5436
Education	p = 0.4954
Marital Status	p = 0.4040

Table 16. Regression Model for Negative Emotional Response (N=283)

Model $R^2 = 0.0846$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	4.59533	.7361648	0.000
Low Complexity	-.2684003	.131241	0.042
Genetic Literacy (GLAC)	-.1778846	.0505359	0.001
Perceived Personal Risk of Cancer	.2070386	.0730683	0.005
Non-Caucasian Race	.193911	.1390355	0.164

Covariates removed by backwards stepwise elimination (p>.20):

Medium Complexity	p = 0.9827
Number of Biological Children	p = 0.9669
Marital Status	p = 0.8983
Education	p = 0.7580
Family History	p = 0.4673
Income	p = 0.4591
Patient-Provider Orientation	p = 0.4208
Age	p = 0.4066

Table 17. Regression Model for Fear (N=283)

Model $R^2 = 0.0842$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	3.187117	.5415543	0.000
Age	-.0138895	.0063239	0.029
Income	.2060448	.0676586	0.003
Perceived Personal Risk of Cancer	.351604	.1014204	0.001
Education	-.1412107	.0822459	0.087

Covariates removed by backwards stepwise elimination (p>.20):

Marital Status	p = 0.9852
Family History	p = 0.6797
Patient-Provider Orientation	p = 0.6459
Low Complexity	p = 0.4534
Non-Caucasian Race	p = 0.2966
Medium Complexity	p = 0.2914
Number of Biological Children	p = 0.2180
Genetic Literacy (GLAC)	p = 0.2153

Table 18. Regression Model for Confusion (N=283)

Model $R^2 = 0.1027$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	5.022499	1.183897	0.000
Low Complexity	-.476199	.1823152	0.009
Genetic Literacy (GLAC)	-.3067455	.0714333	0.000
Perceived Personal Risk of Cancer	.2061744	.1027432	0.046
Non-Caucasian Race	.3428456	.196935	0.083
Patient-Provider Orientation	.2345887	.1388014	0.092

Covariates removed by backwards stepwise elimination (p>.20):

Marital Status	p = 0.9405
Education	p = 0.8326
Family History	p = 0.8288
Age	p = 0.7240
Number of Biological Children	p = 0.6660
Income	p = 0.6250
Medium Complexity	p = 0.2442

Table 19. Regression Model for Frustration (N=283)

Model $R^2 = 0.0261$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	4.676511	1.019378	0.000
Genetic Literacy (GLAC)	-.1700875	.0722473	0.019
Low Complexity	-.2843387	.193279	0.142

Covariates removed by backwards stepwise elimination (p>.20):

Number of Biological Children	p = 0.9556
Medium Complexity	p = 0.8746
Age	p = 0.8040
Income	p = 0.6999
Non-Caucasian Race	p = 0.6264
Education	p = 0.5853
Patient-Provider Orientation	p = 0.4954
Perceived Personal Risk of Cancer	p = 0.4707
Family History	p = 0.4081
Marital Status	p = 0.3953

Table 20. Regression Model for Feeling Different from Others (N=278)

Model $R^2 = 0.0696$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	3.751213	1.168572	0.001
Non-Caucasian Race	.6249188	.2103076	0.003
Low Complexity	-.2831016	.1975088	0.153
Family History	.3039993	.2197748	0.168
Genetic Literacy (GLAC)	-.1513044	.0795485	0.058
Perceived Personal Risk of Cancer	.1983449	.1108937	0.075

Covariates removed by backwards stepwise elimination (p>.20):

Education	p = 0.9258
Income	p = 0.8870
Medium Complexity	p = 0.8587
Age	p = 0.7576
Patient-Provider Orientation	p = 0.6481
Marital Status	p = 0.6179
Number of Biological Children	p = 0.4850

Cancer Genetics Knowledge (Tables 21-23, Figures 12-13)

Multiple linear regression modeling for knowledge measured by a true or false test of cancer genetics facts found no significant differences between complexity levels (medium complexity p=0.958, low complexity p=0.653 compared to the reference high complexity group) (Table 23). Cancer genetics knowledge was measured using a validated knowledge scale comprised of 11 true-false questions related to facts that were covered in all three sets of genetic counseling videos. The average score correct was 8.21 across the three groups (SD 1.68). In general, participants did well on test, but the number of correct answers ranged from 3-11, indicating that some participants struggled or did not retain the information covered while others got all correct. Knowledge scores were slightly negatively skewed, but residual plots of the MLR model constructed showed no patterns indicating non-normality. The number and percentage correct for each knowledge question are reported in Table 22, with the questions ordered from highest overall percentage correct to lowest. Chi squared tests found no significant differences between complexity groups for getting a given question correct, though two statements reached near significance: "A woman who has a sister with an altered BRCA gene has a 50% risk of having an altered gene herself," (p=0.070; high 92.47%, medium 87.63%, low 81.25% correct), and "There are many different genes that cause cancer," (p=0.068; high 90.32%, medium 90.72%, low 97.92% correct).

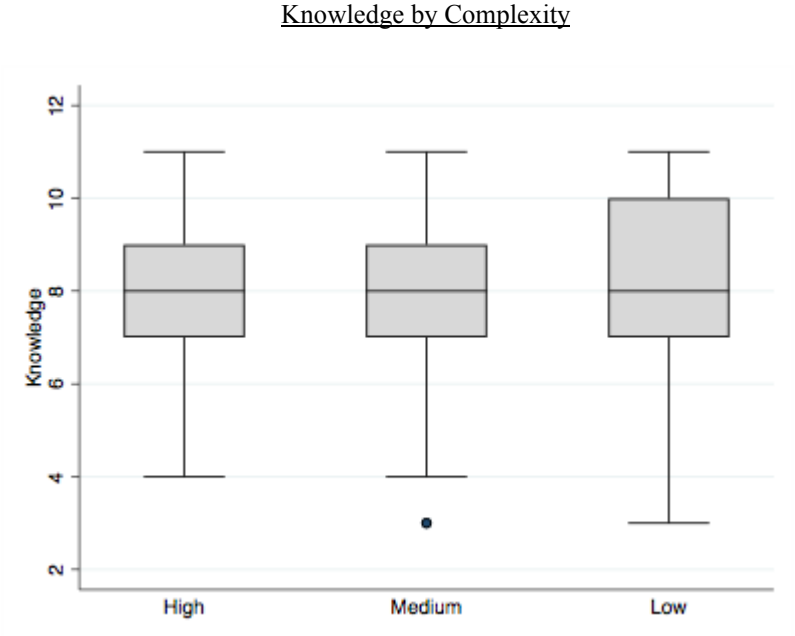
Table 21. Cancer Genetic Knowledge Scores Summary

Cancer Genetics Knowledge		**High Complexity** *N=93*	**Medium Complexity** *N=97*	**Low Complexity** *N=96*	**Combined** *N=286*
	Avg Score (SD) Range 1-11	8.18 (1.74) 4-11	8.19 (1.73) 3-11	8.26 (1.60) 3-11	8.21 (1.68) 3-11

(no significant differences found between complexity levels, Medium p=0.96, Low p=0.65)

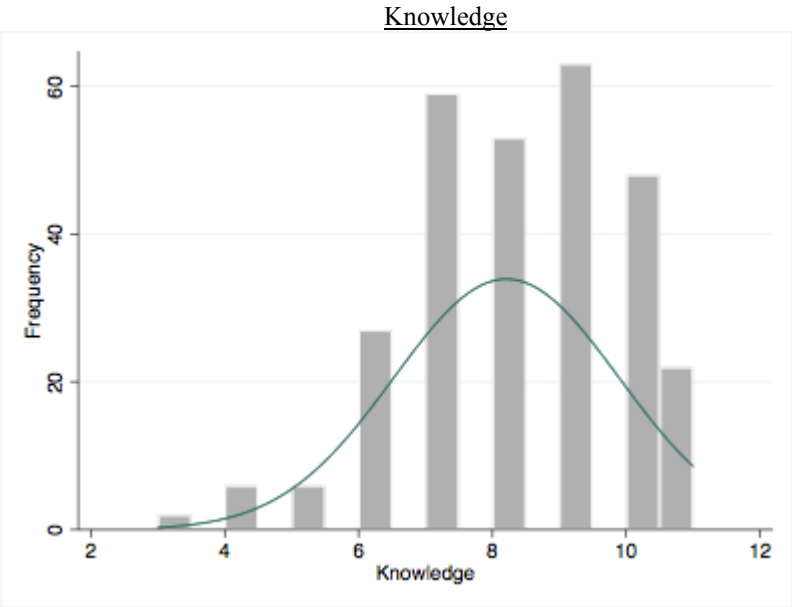
Cancer genetics knowledge scores are summarized. MLR modeling found no significant differences between groups (See Table 23).

Figure 12. Box Plots of Cancer Genetics Knowledge Scores



Boxplots of cancer genetics knowledge are shown by complexity level. MLR was performed to detect significant differences between the complexity levels, and there were no significant differences found through MLR.

Figure 13. Frequency Distribution of Cancer Genetics Knowledge Scores



Distribution of the scores for positive and negative emotional response (N=286) are shown. Knowledge was slightly negatively skewed, but residual plots of the constructed MLR showed no patterns of non-normality.

Table 22. Cancer Genetics Knowledge Measure Summary by Question

	High *N=93*	**Medium** *N=97*	**Low** *N=96*	**Combined** *N=286*
Knowledge Question	Number correct % correct			***chi square*** ***p-value***
A woman who does not have an altered BRCA gene can still get breast or ovarian cancer.	89 95.70%	91 93.81%	94 97.92%	274 95.8% p=0.364
All women who have an altered BRCA gene will get cancer.	88 94.62%	91 93.81%	93 96.88%	272 95.1% p=0.595
There are many different genes that cause cancer.	84 90.32%	88 90.72%	94 97.92%	266 93.0% p=0.068
A father can pass down an altered BRCA gene to his children.	85 91.40%	89 91.75%	89 92.71%	263 92.0% p=0.943
A woman who has a sister with an altered BRCA gene has a 50% risk of having an altered gene herself.	86 92.47%	85 87.63%	78 81.25%	249 87.1% p=0.070
A woman who has her breasts removed can still get breast cancer.	84 90.32%	78 80.41%	82 85.42%	244 85.3% p=0.155
Tests for ovarian cancer often do not detect a tumor until it has spread.	60 64.52%	69 71.13%	69 71.88%	198 69.2% p=0.484
Early-onset breast cancer is less likely due to an altered BRCA gene than is late-onset breast cancer.	56 60.22%	61 62.89%	65 67.71%	182 63.6% p=0.554
Having ovaries removed will definitely prevent ovarian cancer.	50 53.76%	55 56.70%	51 53.13%	156 54.5% p=0.868
One in 10 women have an altered BRCA gene.	39 41.94%	46 47.42%	40 41.67%	125 43.7% p=0.663
One half of breast cancer cases occur in women who have an altered BRCA gene.	40 43.01%	41 42.27%	38 39.58%	119 41.6% p=0.880

Shown are each question included on the cancer genetics knowledge measure and displayed by complexity level. Questions are listed in descending order of correctness. Chi-square tests were performed on each question to determine if there were significant differences between study arms in correctness for each question; no significant differences were found.

Table 23. Regression Model for Cancer Genetics Knowledge (N=283)

Model $R^2 = 0.2106$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	2.418569	1.185735	0.042
Genetic Literacy (GLAC)	.3247648	.0735891	0.000
Non-Caucasian Race	-.9490996	.2030021	0.000
Income	.1179127	.0657582	0.074
Patient-Provider Orientation	.2182437	.1431706	0.129

Covariates removed by backwards stepwise elimination (p>.20):

Medium Complexity	p = 0.9581
Age	p = 0.9501
Perceived Personal Risk of Cancer	p = 0.6887
Low Complexity	p = 0.6530
Education	p = 0.5995
Number of Biological Children	p = 0.4008
Marital Status	p = 0.3835
Family History	p = 0.2432

Genetic Counseling Satisfaction and Perceived Respect from the Genetic Counselor (Table 24-26, Figure 14)

Multiple linear regression (MLR) models exploring the relationship between study arm and genetic counseling satisfaction and perceived respect from the genetic counselor found no significant differences between complexity levels (medium p=0.965, low p=0.473 for satisfaction compared to the reference high complexity group; medium p=0.388 low p=0.997 for perceived respect compared to the reference high complexity group) (Tables 25 and 26). In our study, participants felt generally satisfied with the genetic counseling that they received, with an average satisfaction of 4.01 on a scale from 1 (not satisfied) to 5 (highly satisfied). Beyond satisfaction, participants were asked to what degree they felt respected by the genetic counselor. On average, participants felt respected, with responses averaging 4.19 on a scale from 1 (not respected) to 5 (highly respected). The range for satisfaction for the high complexity level was 1.33-5, which included lower satisfaction scores than both medium (2-5) and low (2.5-5) complexity levels, though satisfaction was not significantly lower in the high complexity group. Respect and satisfaction were both slightly negatively skewed, as the participants generally felt respected and satisfied with their genetic counseling video encounter, but the residual plots constructed from the outcomes' respective MLRs were as expected for normal distributions of data.

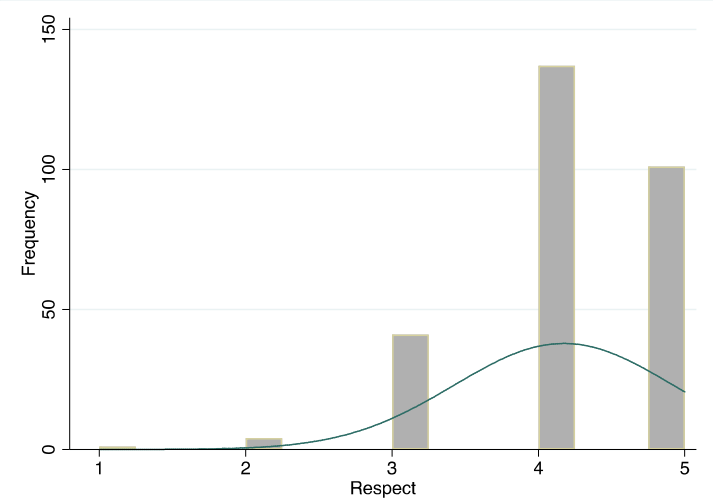
Table 24. Perceived Respect and GC Satisfaction

		High Complexity	**Medium Complexity**	**Low Complexity**	**Combined**
GC Respect		*N=93*	*N=97*	*N=96*	*N=286*
	Avg (SD) Range	4.20 (0.72) 2-5	4.14 (0.80) 1-6	4.21 (0.77) 2-6	4.19 (0.76) 1-6
GC Satisfaction		*N=93*	*N=97*	*N=96*	
	Avg (SD) Range	3.98 (0.75) 1.33-5	4.01 (0.67) 2-5	4.04 (0.60) 2.5-5	4.01 (0.67) 1.33-5

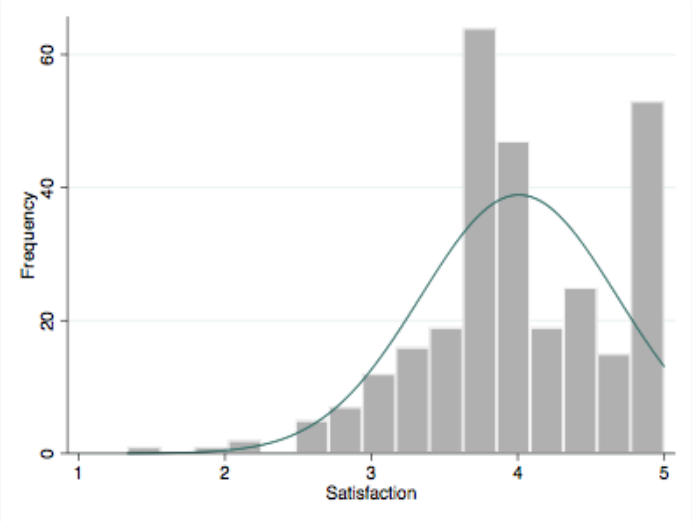
Summaries of perceived respect from the genetic counselor and genetic counseling satisfaction scores are shown. MLR modeling found no significant differences for these outcomes between the three levels of complexity. *(Respect: Medium p=0.388 Low p=0.997; Satisfaction: Medium p=0.965, Low p=0.473)*

Figure 14. Frequency Distribution of GC Respect and Satisfaction

Respect



Satisfaction



Distribution of the scores for perceived respect from the genetic counselor and genetic counseling satisfaction are shown. Both were slightly negatively skewed, but residual plots of the constructed MLR showed no patterns of non-normality.

Table 25. Regression Model for GC Satisfaction (N=283)

Model $R^2 = 0.0653$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	3.403763	.4914263	0.000
Genetic Literacy (GLAC)	.0910883	.0322799	0.005
Number of Biological Children	.0749928	.0333472	0.025
Patient-Provider Orientation (PPOS)	-.1740556	.0631186	0.006
Income	.0511536	.029231	0.081

Covariates removed by backwards stepwise elimination (p>.20):

Medium Complexity	p = 0.9645
Family History	p = 0.8859
Marital Status	p = 0.6752
Education	p = 0.6702
Non-Caucasian Race	p = 0.5421
Low Complexity	p = 0.4734
Age	p = 0.3916
Perceived Personal Risk of Cancer	p = 0.3711

Table 26. Regression Model for Perceived Respect from Genetic Counselor (N=283)

Model $R^2 = 0.0249$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	3.26543	.5122456	0.000
Genetic Literacy (GLAC)	.0511046	.0363825	0.161
Income	.0457046	.0336006	0.175
Number of Biological Children	.0555178	.0379062	0.144

Covariates removed by backwards stepwise elimination (p>.20):

Low Complexity	p = 0.9965
Non-Caucasian Race	p = 0.8662
Marital Status	p = 0.8463
Age	p = 0.7499
Education	p = 0.6224
Patient-Provider Orientation	p = 0.4303
Medium Complexity	p = 0.3880
Perceived Personal Risk of Cancer	p = 0.2359
Family History	p = 0.2186

Verisimilitude and Engagement Outcomes (Tables 27-30, Figure 15)

Verisimilitude was assessed by asking how easy it was for the participants to imagine themselves as the client, how real the genetic counselor seemed, and how similar the video genetic counseling was to other health care the participant had received. MLR with backwards stepwise elimination was used to examine the effect of study arm on the participants' ease of imagining themselves as the client. This analysis showed a significant difference in the low complexity group as compared to the high complexity group (Table 28). Participants in the low complexity group had similarity scores 0.224 lower compared to the high complexity group (p=0.012), when the other covariates in the MLR, number of biological children, perceived personal risk, were held constant. For the measure regarding similarity to other health care, the medium complexity group was significantly different from the high complexity group, and participants in the medium complexity group reported feeling that the video session was 0.279 points more similar compared to those in the high complexity group (p=0.021), when marital status, number of biological children, genetic literacy and patient-provider orientation were held constant (Table 30). No statistically significant differences were found between complexity groups for how realistic the genetic counselor seemed (Tables 28-30).

In general, participants felt it was easy to imagine themselves as the client, with a 3.07 average score on a scale from 1 (very difficult) to 4 (very easy). They also felt that the genetic counselor seemed between somewhat and moderately real with an average score of 2.77 on a scale from 1 (not at all real) to 4 (very real). Table 27 summarizes these scores as well as the frequency of answers for each measure of verisimilitude across the three complexity groups. Across all three groups, 6 women reported that it was

"very difficult" (1) for ease of imagining themselves as the client (1 high, 0 medium, 3 low), 17 reported that the counselor seemed "not at all real" (1) (8 high, 4 medium, 5 low), and 66 reported that the videos were "not at all similar" to other healthcare they have received (26 high, 19 medium, 21 low).

Table 27. Verisimilitude Score and Count Summaries

Verisimilitude Response Score Summary

		High Complexity	**Medium Complexity**	**Low Complexity**	**Combined**
Verisimilitude					
	Ease of playing client role (SD) Range	*N=92* 3.14 (0.69) 1-4	*N=96* 3.15 (0.67) 2-4	***N=96*** **2.93* (0.73)** **1-4**	*N=284* 3.07 (0.70) 1-4
	GC realism (SD) Range	*N=92* 2.74 (0.96) 1-4	*N=96* 2.82 (0.86) 1-4	*N=95* 2.75 (0.86) 1-4	*N=283* 2.77 (0.89) 1-4
	How similar to previous health care (SD) Range	*N=92* 2.04 (0.82) 1-4	***N=95*** **2.32*** **(0.87)** **1-4**	*N=94* 2.19 (0.81) 1-4	*N=282* 2.19 (0.84) 1-4

*p<0.05, **p<0.01, ***p<0.001

Multiple linear regression models were used to detect significant differences between groups, and the low complexity group was found to have lower ease scores than the high complexity group controlling for other covariates in the model (p=0.088). Participants in the medium complexity group found the video genetic counseling experience to be more similar to other healthcare they have had compared to the high complexity group when controlling for the other covariates in the model (p=0.021).

Table 27. Verisimilitude Score Count Summaries continued

Verisimilitude Response Count Summary

Ease: Ease of playing role of the client

Ease	**High Complexity**	**Medium Complexity**	**Low Complexity**	**Combined**
	N=92	*N=96*	*N=96*	*N=284*
Very Difficult	1 (1%)	0 (0%)	5 (5.2%)	6 (2.1%)
Hard	13 (14.1%)	15 (15.6%)	14 (14.6%)	42 (14.8%)
Easy	50 (54.3%)	52 (54.2%)	60 (62.5%)	162 (57.0%)
Very Easy	28 (30.4%)	29 (30.2%)	17 (17.7%)	74 (26.1%)

Reality: How real the genetic counselor seemed

Reality	**High Complexity**	**Medium Complexity**	**Low Complexity**	**Combined**
	N=92	N=96	n=95	N=283
Not at all real	8 (8.7%)	4 (4.2%)	5 (5.3%)	17 (6.0%)
Somewhat real	33 (35.9%)	33 (34.4%)	35 (36.8%)	101 (35.7%)
Real	26 (28.3%)	35 (36.5%)	34 (35.8%)	95 (33.6%)
Very real	25 (28.2%)	24 (25.0%)	21 (22.1%)	70 (24.7%)

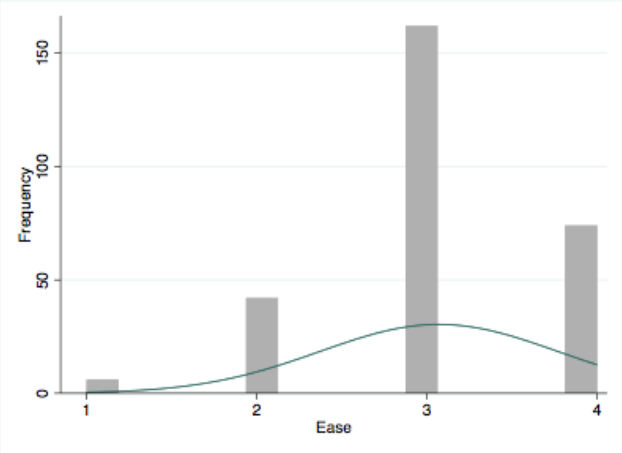
Similarity: How similar the experience was to other health care experiences

Similarity	**High Complexity**	**Medium Complexity**	**Low Complexity**	**Combined**
	N=92	N=95	n=94	N=281
Not at all similar	26 (28.3%)	19 (20.0%)	21 (22.3%)	66 (23.5%)
Somewhat similar	39 (42.4%)	32 (33.7%)	36 (38.3%)	107 (38.1%)
Similar	24 (26.1%)	38 (40.0%)	35 (37.2%)	97 (34.5%)
Very similar	3 (3.3%)	6 (6.3%)	2 (2.1%)	11 (3.9%)

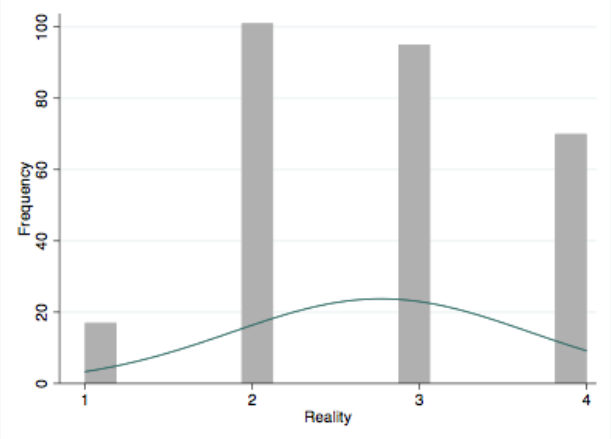
Scores for measures of verisimilitude (ease, realism, similarity) are summarized for each complexity level

Figure 15. Frequency Distributions of Measures of Verisimilitude

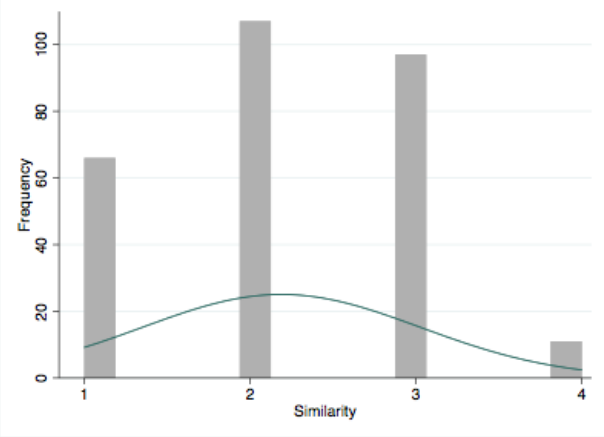
Ease



Reality



Similarity



Distribution of the scores for verisimilitude are shown (ease of imagining self as the client, reality of the genetic counselor, and similarity to other healthcare).

Table 28. Regression Model for Ease of Playing Role of the Client(N=281)

Model $R^2 = 0.0344$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	3.390511	.1540349	0.000
Low Complexity	-.2235192	.0880134	0.012
Number of Biological Children	-.0491097	.0340557	0.150
Perceived Personal Risk of Cancer	-.0717508	.049261	0.146

Covariates removed by backwards stepwise elimination (p>.20):

Genetic Literacy (GLAC)	p = 0.9883
Age	p = 0.8782
Medium Complexity	p = 0.8387
Patient-Provider Orientation	p = 0.8382
Marital Status	p = 0.7962
Income	p = 0.5965
Education	p = 0.5663
Non-Caucasian Race	p = 0.5029
Family History	p = 0.4298

Table 29. Regression Model for Perceived Reality of Video Genetic Counselor (N=280)

Model $R^2 = 0.0786$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	2.456355	.6516473	0.000
Household Income	.0986419	.03885	0.012
Number of Biological Children	.1231756	.0440463	0.006
Patient-Provider Orientation (PPOS)	-.2023654	.0833828	0.016
Family History	.1742183	.1219828	0.154
Genetic Literacy (GLAC)	.0632272	.0430887	0.143

Covariates removed by backwards stepwise elimination (p>.20):

Perceived Personal Risk of Cancer	p = 0.8578
Marital Status	p = 0.7652
Low Complexity	p = 0.7504
Non-Caucasian Race	p = 0.6779
Medium Complexity	p = 0.6213
Age	p = 0.3421
Education	p = 0.2349

Table 30. Regression Model for Similarity to Other Healthcare (N=278)

Model $R^2 = 0.0682$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	1.966742	.6349723	0.002
Medium Complexity	.2796464	.1202034	0.021
Genetic Literacy (GLAC)	.0914263	.0411467	0.027
Number of Biological Children	.0856325	.0422025	0.043
Patient-Provider Orientation	-.2221813	.0795998	0.006
Low Complexity	.1696617	.1211165	0.162
Marital Status	-.0703532	.0520976	0.178

Covariates removed by backwards stepwise elimination (p>.20):

Age	p = 0.9837
Family History	p = 0.6590
Income	p = 0.4870
Perceived Personal Risk of Cancer	p = 0.4523
Education	p = 0.4090
Non-Caucasian Race	p = 0.2872

Engagement (Tables 31-32)

When asked how often participants verbally or mentally responded to the genetic counselor's questions, participants tended to report being engaged. Backwards stepwise MLR found no significant differences between complexity levels (medium p=0.918; low p=0.736 compared to high complexity) when controlling for the included covariates in the model, including family history of a first degree relative with breast, ovarian, and/or prostate cancer, and genetic literacy (Table 32). Reported engagement averaged 3.62, between (3) "about half the time" and (4) "most of the time" on a scale from responding verbally or mentally (1) "not at all" to (5) "all of the time". In all groups, the range of engagement across participants covered 1 through 5, indicating that there were participants that reported engaging not at all and others that reported engaging all the time.

Table 31. Self-Reported Engagement Scores and Count Summary

Self-Reported Engagement Scores

		High Complexity	**Medium Complexity**	**Low Complexity**	**Combined**
Engagement		*N=93*	*N=96*	*N=96*	*N=285*
	Avg (SD) Range	3.61 (1.16) 1-5	3.62 (1.10) 1-5	3.63 (1.08) 1-5	3.62 (1.11) 1-5

Self-reported engagement scores for each complexity level are shown. Multiple linear regression models were used to determine if there were between-group differences, and none were found (*Medium p=0.918, Low p=0.736).*

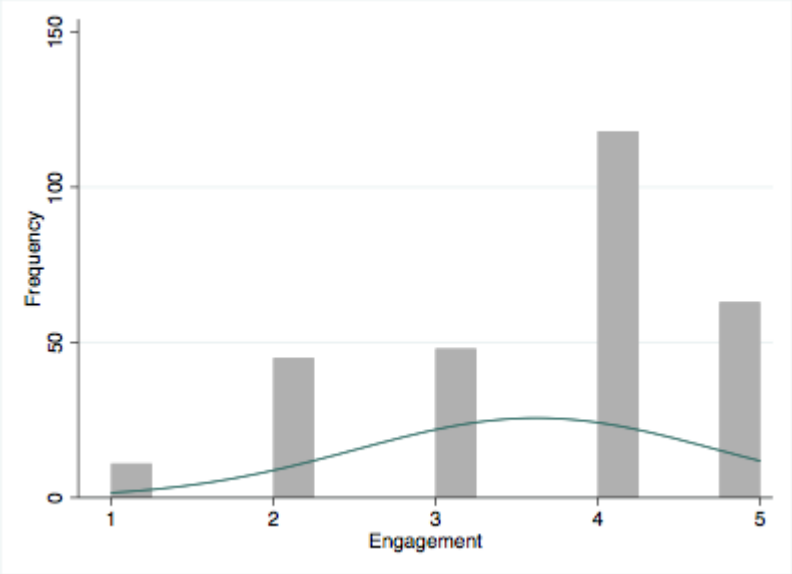
Self-Reported Engagement Count Summary

Similarity	**High Complexity**	**Medium Complexity**	**Low Complexity**	**Combined**
	N=93	N=96	N=96	N=285
Not at all	4 (4.3%)	3 (3.1%)	4 (4.2%)	11 (3.9%)
Some of the time	16 (17.2%)	17 (17.7%)	12 (12.5%)	45 (15.8%)
About half of the time	15 (16.1%)	14 (14.6%)	19 (19.8%)	48 (16.8%)
Most of the time	35 (37.6%)	42 (43.8%)	41 (42.7%)	118 (41.4%)
All of the time	23 (24.7%)	20 (20.8%)	20 (20.8%)	63 (22.1%)

Counts for the number of responses to the question “When the genetic counselor asked you a question, how often did you answer the question (out loud or in your head)?”

Figure 16. Frequency Distributions of Self-Reported Engagement

Engagement



Distribution of the scores for self-reported engagement are shown here.

Table 32. Regression Model for Engagement (N=282)

Model $R^2 = 0.0308$	Coefficients		
	β	Std. Error	*p*-value
(Constant)	1.764727	.7277162	0.016
Genetic Literacy (GLAC)	.1298352	.0520003	0.013
Family History *	.2071823	.1542193	0.180

* Family History: Having one or more first degree relative with breast, ovarian, and or/prostate cancer.

Covariates removed by backwards stepwise elimination (p>.20):

Medium Complexity	p = 0.9183
Patient-Provider Orientation	p = 0.8544
Non-Caucasian Race	p = 0.8242
Low Complexity	p = 0.7356
Age	p = 0.6696
Education	p = 0.6633
Marital Status	p = 0.6526
Income	p = 0.5956
Perceived Personal Risk of Cancer	p = 0.4732
Number of Biological Children	p = 0.2249

AIM 2: *Personal Characteristics and Multivariate Models of Outcomes*

The purpose of Aim 2 was to examine if clients' personal characteristics (demographics, perceived personal risk of cancer, genetic literacy, and patient-provider orientation) were associated with the genetic counseling session outcome measures, and whether there were moderating effects of these personal factors on the relationships between the complexity level and the outcomes. Bivariate analysis was done to look for correlations and directionality of relationships between personal characteristics and outcomes (Appendix E). Multiple linear regression models with backwards stepwise elimination were constructed to determine which, if any, characteristics were significantly associated with outcomes. For the multiple linear regression models, reference groups for categorical variables were: high complexity, Caucasian race, and having no first degree relative with breast, ovarian, or prostate cancer.

Decisional Outcomes

Chi square tests for categorical covariates and multinomial logistic regression tests for continuous covariates were used to determine whether personal characteristics were significantly associated with genetic test decision. Multinomial logistic regression models were created using genetic test decision as the outcome and the personal characteristic as the independent variable in individual separate models, with no other covariates included in the model.

(1) Genetic Test Decision

Significant differences were detected for participant age, perceived personal risk, and patient-provider orientation in the decision to have genetic testing following the genetic counseling videos (Table 41). The model predicted that as age increased one year,

the odds of choosing "No" over "Yes" was 1.030 greater (β =0.0292, p=0.0). For every increase in unit of patient-provider orientation towards a preference for greater patient-centeredness,, the odds of choosing "Maybe" over "Yes" was 2.016 greater (p=0.022). No other personal characteristics were found to be significantly associated with genetic test decision.

(2) Decisional Conflict

The relationships between participants' characteristics and outcomes after watching the videos were explored in the previously described multivariate models. Genetic literacy and perceived personal risk of cancer were the only characteristics that met statistical significance in the generated model for decisional conflict (Table 11). For genetic literacy, for each increase of one unit of genetic literacy (i.e. from 12 to 13 or 5 to 6), there was a 0.0810 decrease in decisional conflict score (p=0.006, N=283, R^2=0.0761) controlling for the other covariates included in the model. This means that as genetic literacy increased, decisional conflict decreased, and thus, those with low literacy tended to be more conflicted with their decision. With regard to personal perceived risk, for each one unit increase in perceived personal risk of cancer (i.e. "3 - about the same as average" to "4 - higher than average") there was a 0.0928 increase in decisional conflict (p=0.025).

Table 33. Test Statistics for Test Decision Differences between Personal Characteristics

	X^2 p-value	**Mlogit* Model (Maybe vs. Yes) β (SE) *p-value***	**Calculated Odds Ratio (e^B)**	**Mlogit Model (No vs. Yes) β (SE) *p-value***	**Calculated Odds Ratio (e^B)**
Age (N=252)		0.00141 (0.0986) *p=0.886*	1.001	**0.02957 (0.0122) *p=0.016***	**1.030**
Non-Caucasian Race	*p=0.587* (chi2)				
Education Level		-0.173 (0.116) *p=0.136*	0.841	0.00730 (0.159) *p=0.963*	1.007
Household Income		-0.0890 (0.0983) *p=0.365*	0.915	0.0423 (0.126) *p=0.737*	1.043
Marital Status	*p=0.304* (chi2)				
Biological Children		0.0723 (0.111) *p=0.513*	1.075	0.118 (0.137) *p=0.390*	1.125
Family History**	*p=0.698* (chi2)				
Personal perceived risk of cancer		**0.382 (0.167) *p=0.022***	**1.47**	-0.0852 (0.200) *p=0.670*	0.918
GLAC		-0.115 (0.105) *p=0.272*	0.891	0.0359 (0.1467) *p=0.807*	1.037
Patient-Provider Orientation		0.237 (0.214) *p=0.269*	1.267	**0.701 (0.295) *p=0.017***	**2.016**

*Mlogit: Multinomial logistic
**Family history = having at least one first degree relative with breast, ovarian, and/or prostate cancer.

Multiple logistic regression models and chi square tests were performed to detect significant differences between test decisions based on continuous personal characteristics.
For the multiple logistic regression, the reference group was treated as a "Yes" answer to pursuing genetic testing.
Chi-square tests were performed to detect significant differences between test decisions based on categorical personal characteristics.

Affective Outcomes

(1) Positive Emotional Response:

The model for positive emotion included the statistically significant personal characteristics covariates patient-provider orientation ($p<0.001$) and age ($p=0.011$) ($N=283$, $R^2=0.0898$) (Table 13). For each increase in unit of genetic literacy, there was a 0.145 increase in positive emotion score, controlling for the rest of the covariates in the model. For patient-provider orientation, one unit increase toward greater preference for patient-centered interactions corresponded with a decrease in positive emotion by 0.48, controlling for the other covariates in the model. Each increase of one year in age corresponded to a 0.015 increase in positive emotion score, controlling for the other covariates in the model. More generally, individuals with lower literacy, higher preference for patient centered interactions, and younger age tended to report less strong positive emotional responses.

By examining each emotion individually, a more detailed characterization of emotional responses was made (Tables 14 and 15). With each one year increase in age, there was a 0.0163 increase in reported ease of mind ($p=0.014$) and a 0.0141 increase in reported confidence ($p=0.036$) with all other covariates held constant (Table 14). This suggests older women tended to report stronger positive emotions than younger women. For ease of mind, for each level of increase in education completed (i.e. college to graduate school), there was a 0.188 decrease in reported ease of mind ($p=0.025$) holding all other covariates constant, indicating that highly educated women had lower levels of ease of mind compared to those with less education.

Patient-provider orientation was also associated with ease of mind and confidence (Tables 14 and 15). For each increase in unit (i.e. 5 to 6) in the PPOS (toward greater preference for patient-centered care), there was a decrease of 0.447 in reported ease of mind (p=0.002) and a decrease of 0.454 in reported confidence (p=0.001) while holding all other covariates constant. This suggests that participants who are more highly oriented towards patient-centeredness tended to report feeling less at ease and less confident after interacting with the genetic counselor in this study. Genetic literacy was found to be positively associated with confidence, such that with each increase in unit of literacy, there was a 0.201 increase in reported confidence (p=0.006), suggesting that participants with higher genetic literacy tended to feel more confident after the video genetic counseling session that those with lower genetic literacy.

(2) Negative Emotional Response:

Regression models were also created for negative emotion as well as each of the individual negative emotions on the emotional response measure (Tables 16-20). Covariates included in the model negative emotional model that reached significance were perceived personal risk for cancer (p=0.005), genetic literacy (p=0.001), along with low complexity (p=0.042) (N=283, R^2=0.0846) (Table 16). Perceived personal cancer risk was positively associated with strength of negative emotions; for each increase in one unit of personal perceived risk of cancer (i.e. “3 - about the same as average” to “4 - higher than average”), there was a 0.207 increase in the strength of reported negative emotions (p=0.005), holding complexity level, genetic literacy, and race constant. Genetic literacy was also associated with negative emotional responses, such that participants with higher genetic literacy tended to report lower levels of negative

emotions. For each increase of one unit of genetic literacy, there was a decrease of 0.178 in strength of reported negative emotions (p=0.001), holding complexity level, perceived personal risk of cancer, and race constant, indicating that participants with lower genetic literacy tended to report stronger negative emotions than those with higher literacy.

The MLR model constructed for fear demonstrated statistically significant effects of age (p=0.029), income (p=0.003), and perceived personal risk of cancer (p=0.001)(N=283, R^2=0.084) (Table 17). Age was negatively associated with fear; with each increase in year, reported strength of fear feelings decreased by 0.0139 (p=0.029), controlling for personal perceived risk for cancer, education, and income. Income was positively associated with fear, such that for each bracket of income increase (i.e. from $50,000-$75,000 to $75,000-$100,000), there was a 0.206 increase in the reported strength of fear emotional response (p=0.003), controlling for the other variables in the model. Perceived personal risk of cancer was also positively associated with fear, such that for every unit increase in perceived personal risk, there was a 0.351 increase in reported fear (p=0.001). Although not associated with fear, low genetic literacy was the only variable significantly associated with stronger feelings of frustration, such that every unit increase in literacy corresponded to a 0.170 decrease in frustration (p=0.019), controlling for low complexity in the MLR model for frustration (Table 19).

The MLR model for the negative emotion feeling "different from others" demonstrated a statistically significant relationship with only a single variable, racial group (p=0.003), (N=278, R^2=0.0696) (Table 20). Non-Caucasian participants reported feeling more different from others after watching the videos than did those in the Caucasian group. Compared to the Caucasian group, the non-Caucasian group reported

scores on the "different from others" variable that were 0.625 higher than those in the Caucasian group, controlling for genetic literacy, complexity, family history, and personal perceived risk (p=0.003).

In addition to differing by study arm, the negative emotion confusion was also associated with multiple personal characteristics. The MLR for confusion demonstrated statistically significant differences for genetic literacy (p<0.001) and personal perceived risk (p=0.046)(N=283, R^2=0.1027) (Table 18). Perceived personal risk was positively associated with the feeling of confusion, such that for each unit increase in perceived risk for cancer (i.e. "3 - about the same as average" to "4 - higher than average"), there was an increase in reported confusion scores of 0.206 (p=0.046), holding other covariates constant. Genetic literacy was negatively associated with feelings of confusion; as genetic literacy increased by one unit, the strength of feelings of confusion decreased by 0.316 points (p<0.001), holding the other covariates in the model constant.

(3) Genetic Counseling Satisfaction and Perceived Respect from the Genetic Counselor:

Similar to outcomes for emotional response, genetic literacy and patient-provider orientation were each associated with satisfaction after the genetic counseling session. Statistically significant demographic characteristics in the MLR for satisfaction included genetic literacy (p=0.005), number of biological children (p=0.025), and patient-provider orientation (p=0.006)(N=283, R^2=0.0653) (Table 24). As genetic literacy increased by one unit, satisfaction also increased by 0.88 units (p=0.011), indicating that individuals with higher genetic literacy tended to be more satisfied. Individuals with a higher patient-centeredness orientation tended to be less satisfied than those who were more disease- or

doctor-centered, as one unit increase on the PPOS was associated with a 0.156 decrease in satisfaction (p=0.021). Respect from the genetic counselor did not differ significantly across any of the personal characteristics, and the average reported respect was generally high (~4 out of 5), as discussed previously (Table 26).

Cognitive Outcomes

(1) Cancer Genetics Knowledge:

Beyond gathering emotional and affective responses, participants were tested on their cancer genetics knowledge after watching the videos. The MLR model for knowledge included statistically significant covariates genetic literacy ($p<0.001$), and racial group ($p<0.001$) ($N=283$, $R^2=0.2106$) (Table 23). The R^2 value for this model accounts for 21% of the variance in the model, which captures more of the variance than the other outcome models. As a group, the non-Caucasian racial group scored 0.949 lower on the knowledge measure than the Caucasian reference group, while holding the other covariates in the model, genetic literacy, patient provider orientation, and income constant. Genetic literacy was also associated with cancer genetics knowledge; higher genetic literacy was associated with higher scores on the knowledge test. For every unit increase in genetic literacy, there was a 0.352 increase in knowledge score, while controlling for the rest of the model's included covariates.

Verisimilitude

In order to gauge how realistic the video session and genetic counselor seemed and how easy it was for the participant to play the role of the client, questions were asked to address the verisimilitude of the experience. For the MLR model for "ease," or how

easy it was for participants to play the role of the client, no personal characteristics included in the model were significantly associated with ease.

Statistically significant demographic characteristics included in the MLR model for perceived reality of the genetic counselor included patient-provider orientation (p=0.016), income (p=0.012), and number of biological children (p=0.006) (N=280, R^2=0.0786) (Table 29). Participants with higher patient-provider scores (PPOS) toward more patient-centered orientation felt that the counselor seemed less real than those with lower scores. For every point increase on the PPOS, the perceived reality of the video genetic counselor decreased by 0.202, controlling for the other covariates in the model. Household income and number of biological children were positively associated with perceived reality. For each increase in bracket of income, there was an increase of perceived reality by 0.0986, and for each added biological child, there was an increase of perceived reality of 0.123 controlling for all other covariates in the model in each case.

Genetic literacy and patient-provider orientation were also associated with how similar the participants felt the video genetic counseling session was to other healthcare they had received (Table 30). The MLR for the similarity measure included genetic literacy (p=0.027), number of biological children (p=0.043), patient-provider orientation and (p=0.006) (Table 30). Genetic literacy was positively associated (0.0914 increase in similarity for every unit increase of genetic literacy while controlling for all covariates, p=0.027, while patient-provider orientation was negatively associated with similarity (0.222 decrease in similarity for every unit increase in the PPOS while controlling for all other covariates, p=0.006. Number of biological children was positive associated, and for each increase of one child, there was a 0.0856 increase in similarity to other healthcare

while controlling for the other covariates in the model (p=0.043).

Self-Reported Engagement

As a way of approximating how engaged or active participants were in the hypothetical genetic counseling session, participants were asked on a scale of 1-5 how often they engaged verbally or mentally with the video genetic counselor when she asked them a question. The only statistically significant demographic characteristics in the MLR model for engagement was genetic literacy (p=0.013) (N=282, R^2=0.0308) (Table 32). For every unit increase in genetic literacy, engagement scores increased 0.129 (p=0.013) controlling for family history, indicating that individuals with lower literacy tended to feel less engaged in the session.

AIM 2.1: *Personal Characteristics as Modifiers*

Another aim of this study was to examine not only if personal characteristics were associated with genetic counseling outcomes, but if they had a moderating effect on the relationship between communication complexity and those outcomes. For the decision to have genetic testing, stratified multinomial logistic regressions were run to examine differences in effects on testing decision by complexity level. Stratified models were only created for the personal characteristics found to be associated with the test decision (age, perceived risk of cancer, and patient-provider orientation).

For affective and cognitive outcomes, stratified regression models by complexity level were created to include a single outcome with a single personal characteristic to compare the effects of complexity on the relationship between personal characteristics and outcomes. Only personal characteristics that were found to have an association with those outcomes (as described previously) were used in the stratified models. Multiple linear regression models were also created using interaction terms with communication complexity. Personal perceived cancer risk, age, race, genetic literacy, patient-provider orientation, education, and income were each run individually as interaction terms with complexity level in separate multiple linear regression models for each outcome.

Decisional Outcomes

Stratified multinomial logistic regression was used to detect effect modification of complexity level on personal characteristic covariates and genetic test decision. Effect modification of complexity level on personal characteristics and outcomes were found for personal perceived risk of cancer and patient-provider orientation (Tables 33 and 34). Within the high complexity group, the odds of choosing “Maybe” or “No” were not

significantly different from the odds of choosing "Yes" as personal perceived risk of cancer increased. However, the odds of non-yes responses vs "yes" responses did tend to vary as personal perceived risk of cancer increased in the medium and low complexity levels. For each unit increase in personal perceived risk of cancer, there was a 2.53 greater odds of choosing "Maybe" over "Yes" and a 3.43 greater odds of choosing "No" over "Yes" in the medium complexity condition (p=0.007 and p=0.009, respectively). In the low complexity condition, the odds of choosing "No" vs. the odds of choosing "Yes" for every increase in unit of perceived personal risk of cancer was 0.437 lower (p=0.026), indicating that in the low complexity condition, individuals with higher perceived personal risk were less likely to choose "No" over "Yes."

Effect modification was also present for complexity level on patient provider orientation (PPOS) and the genetic test decision. There were no differences in odds of choosing "Maybe" or "No" over "Yes" in the high complexity group as PPOS increased, but there were differences in the medium and low complexity groups. In the medium complexity group, for every increase in unit of the PPOS toward preference for grater patient centered interactions, there was a 2.66 greater odds of choosing "No" over "Yes". However, this finding was only marginally statistically significant. In the low complexity group for each unit increase in the PPOS, there was a 2.23 greater odds of choosing "Maybe" over "Yes" and a 2.93 greater odds of choosing "No" over "Yes."

Table 34. Multinomial Logistic Regression Models for Personal Characteristics that Modify the Effect of Complexity Level on Genetic Test Decision

Personal Perceived Risk

High Complexity LR chi2(2)=1.49 N=93					
			β (SE)	**p-value**	**Odds Ratio**
		Maybe	.1487 (.282)	0.597	-
		No	-.315 (.340)	0.354	-
Medium Complexity LR chi(2)=13.09 N=97					
			β (SE)	**p-value**	**Odds Ratio**
		Maybe	**.928 (.347)**	**0.007**	**2.53**
		No	**1.234 (.473)**	**0.009**	**3.43**
Low Complexity LR chi2(2) = 8.08 N=95					
			β (SE)	**p-value**	**Odds Ratio**
		Maybe	0.308 (.289)	0.286	-
		No	**-0.827 (.373)**	**0.026**	**0.437**

Table 34. Multinomial Logistic Regression Models for Personal Characteristics that Modify the Effect of Complexity Level on Genetic Test Decision cont.

Patient-Provider Orientation

High Complexity LR chi2(2) = 0.17 N=93					
			β (SE)	**p-value**	**Odds Ratio**
		Maybe	.166 (.413)	0.687	-
		No	.0174 (.494)	0.972	-
Medium Complexity LR chi2(2) = 4.93 N=97					
			β (SE)	**p-value**	**Odds Ratio**
		Maybe	.928 (.342)	0.703	-
		No	.981 (.518)	0.058	2.66
Low Complexity LR chi2(2) = 7.39 N=96					
			β (SE)	**p-value**	**Odds Ratio**
		Maybe	**.803 (.395)**	**0.042**	**2.231**

Affective Outcomes

Genetic literacy was found to modify the relationship between communication complexity and satisfaction as well as the relationship between communication complexity and respect. Stratified regression model analyses by complexity level were performed to detect whether the relationships between genetic literacy and satisfaction differed from zero. Regression models including satisfaction and genetic literacy for each complexity level found that the changes in satisfaction by genetic literacy were not significantly different from zero for the medium and low levels ($p=0.922$, $p=0.211$), but the regression coefficient was significantly different from zero for the high complexity level ($p=0.010$). For individuals in the high complexity group only, for every unit increase in genetic literacy, there was an increase in satisfaction of 0.1632 points, with no other variables in the regression model. Thus, individuals with lower genetic literacy tended to be less satisfied than those with high genetic literacy only in the high communication complexity group.

Multiple linear regression models for satisfaction including complexity, genetic literacy, and the interaction terms between complexity and genetic literacy were completed to further explore differences between the groups. As seen in the stratified regression analyses, the interaction terms indicated that the relationships between genetic literacy and satisfaction differed between the high complexity vs. the medium complexity group ($p=0.047$)Although it was not statistically significant, there was a similar trend present comparing the high with the low complexity groups ($p=0.176$).

Stratified regression modeling by complexity level for respect and genetic literacy

had a similar trend, with only the high complexity level having a significant relationship. The medium and low complexity groups did not show significant relationships between genetic literacy and respect (p=0.266 and p=0.326, respectively). In the high complexity group, for each increase in unit of genetic literacy, there was a 0.184 increase in respect (p=0.002) with no other variables in the regression model. Similar to satisfaction, individuals with lower genetic literacy tended to feel less respected by the video genetic counselor only in the high complexity group. MLR modeling including interaction terms for complexity level together by genetic literacy showed that the relationships between genetic literacy and respect tended to differ when comparing the high complexity group with the medium complexity group (p=0.004). A similar but non-significant trend was seen comparing the high with the low complexity groups with regard to respect (p=0.153).

No other affective outcomes had significant interaction terms, indicating no further evidence of effect modification.

Figure 17. Best Fit Linear Regression Model of Genetic Literacy and Satisfaction by Communication Complexity

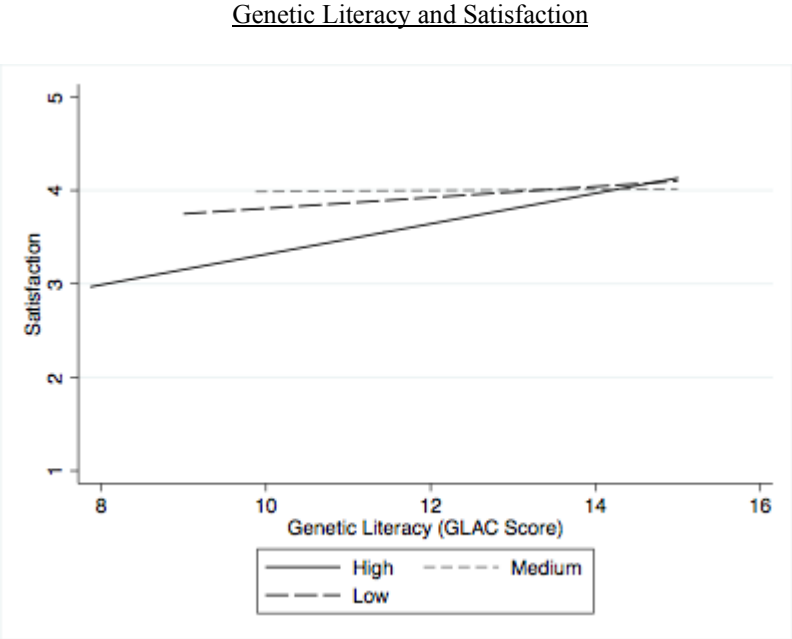


Table 35. Stratified Regression Models for Genetic Literacy and Satisfaction by Complexity

Satisfaction

	High		Medium		Low	
	β (SD)	**p-value**	**β (SD)**	**p-value**	**β (SD)**	**p-value**
GLAC	**0.1632 (.0622)**	**0.010**	.00540 (.0551)	0.922	.0584 (.0464)	0.211

Table 36. Summary of Genetic Literacy and Interaction Term Effects with Communication Complexity on Satisfaction

Genetic Literacy

Interaction Term	**Interaction β Coefficient**	**p-value**
Satisfaction*Medium Complexity	**-0.158**	**p=0.047**
Satisfaction*Low Complexity	-0.105	p=0.176

Figure 18. Best Fit Linear Regression Model of Genetic Literacy and Respect by Communication Complexity

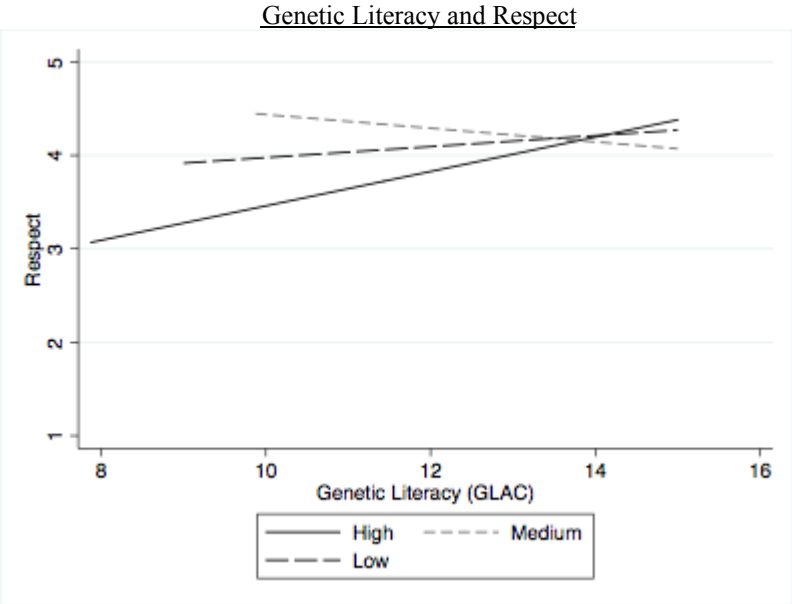


Table 37. Stratified Regression Models for Genetic Literacy and Respect by Complexity

Respect

	High		Medium		Low	
	β (SD)	**p-value**	**β (SD)**	**p-value**	**β (SD)**	**p-value**
GLAC	**0.184 (0.0588)**	**0.002**	-0.0732 (0.0654)	0.266	0.0589 (0.0596)	0.326

Table 38. Summary of Genetic Literacy and Interaction Term Effects with Communication Complexity on Respect

Interaction Term	**Interaction β Coefficient**	**p-value**
Respect*Medium Complexity	**-0.26**	**p=0.004**
Respect*Low Complexity	-0.125	p=0.153

Cognitive Outcomes

Cancer genetics knowledge was the only other genetic counseling outcome affected by interactions between personal characteristics and complexity level. Stratified regression models showed that there was a significant relationship between knowledge and PPOS only in the medium complexity group. Individuals with a doctor-centered preference (low PPOS) tended to have lower knowledge scores than those with a more patient-centered style preference (high PPOS) when assigned to a medium complexity genetic counselor (Figure 19). Sensitivity analysis removing the outliers in the medium complexity group with the lowest three knowledge scores did not alter this relationship. This linear relationship was not seen in the high or low complexity groups, as in those groups the relationship between PPOS and knowledge was not significantly different from zero ($p=0.301$ for high, $p=0.284$ for low complexity).

Multiple regression models for knowledge including PPOS, complexity, and the interaction terms between complexity level and PPOS were constructed to examine the effects of the interaction term. this showed that the relationship between PPOS and knowledge in the medium complexity group was significantly different from that seen in the high complexity group ($p=0.025$). This trend was not observed in the low complexity group compared to the high complexity group ($p=0.883$).

Figure 19. Best Fit Linear Regression Models of Patient-Provider Orientation and Knowledge by Communication Complexity

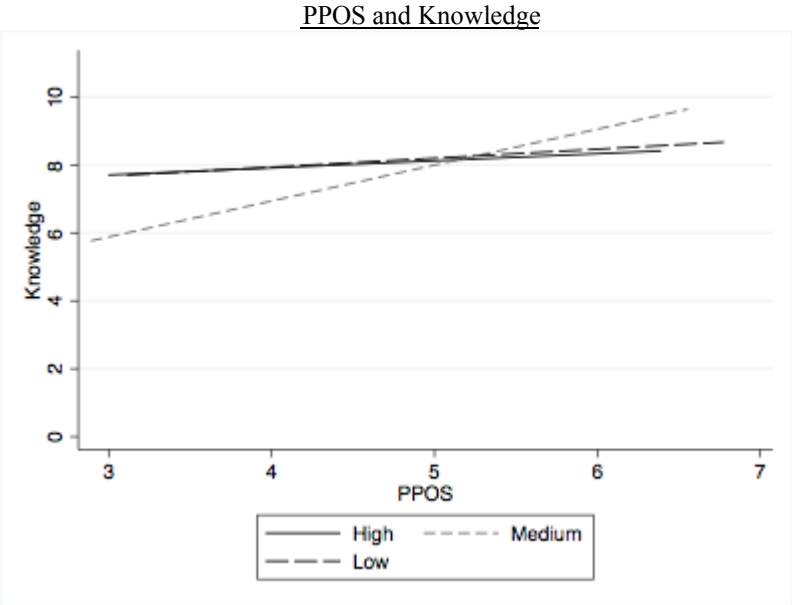


Table 39. Summary of Patient-Provider Orientation and Complexity Interaction Terms

Interaction Term	**Interaction β Coefficient (SE)**	**p-value**
PPOS*Medium Complexity	**0.847 (.377)**	**p=0.025**
PPOS*Low Complexity	0.0556 (.379)	p= 0.883

Table 40. Stratified Regression Models for PPOS and Knowledge by Complexity

Knowledge

	High		Medium		Low	
	β (SD)	**p-value**	**β (SD)**	**p-value**	**β (SD)**	**p-value**
PPOS	0.208 (0.301)	0.490	**1.056 (0.241)**	**<0.001**	0.264 (0.245)	0.284

DISCUSSION

Communication Complexity

While our study aimed to detect differences in genetic counseling outcomes based on the level of complexity of the communication of genetic information, we found that in our cohort of 286 women without a personal history of cancer, there were only a few major effects of communication complexity alone. We found that in the low complexity condition, overall negative emotional response and confusion were felt significantly less strongly compared to the high complexity group. While it was encouraging to find that lowering complexity also lowered confusion and negative emotional response, we did not find that lowering complexity and thus, lowering confusion, improved knowledge scores or other outcomes among this group of participants. While participants in the low complexity group felt less confused, they did not necessarily learn the information better than those in the high complexity group.

There were no main effects of communication complexity for outcomes of genetic test decision, positive emotional response, knowledge, perceived respect, or satisfaction. Of note, the medium complexity group, but not the low complexity group, had a statistically significantly higher reported level of decisional conflict compared to the high complexity level. Decisional conflict relates to the "condition of hesitation and doubt about a forthcoming decision" (Katapodi et al., 2011), and in our study, participants deliberated about the decision to proceed with genetic testing after having video genetic counseling for a hypothetical scenario of having a sister affected with cancer. Participants in the medium complexity group were given as much informational detail as the higher complexity group (though using more plain, less complex language). The medium

complexity group also offered as many turns to speak or to be engaged with the video genetic counselor as the low complexity group. In the high complexity level, the genetic counselor talked for 21 minutes and had seven opportunities for the participant to engage or interact verbally or mentally, while in the medium complexity level, she talked for 18 minutes and gave 17 opportunities. In the low complexity level, the genetic counselor only talked for 12 minutes and also gave 17 opportunities for the participant to have a turn to engage. The content of the genetic counseling session across all three arms involved aspects of receiving uncertain or uninformative test results. Hearing the detailed information both in a more accessible and more interactive way may have created additional conflict in the medium complexity group as they attempted to make sense of the nuances of what they heard and to understand the uncertain nature of the testing. Contrastingly, the medium complexity condition could have been both an overload of information and a burden to remain interactive in the session while also not receiving real-time answers to their questions. It is also possible that the combination of more detailed information and a perceived burden of being asked to interact with the video genetic counselor during the hypothetical medium complexity session may have negatively affected how certain the participants felt about their decision. There were no main effects of complexity on the genetic test decision, so participants in this group tended to feel slightly more conflicted overall but did not choose one test decision more frequently than expected based on responses in the other two study arms. One aspect of decisional conflict entails "lacking needed information to make [a] decision" (Katapodi et al., 2011). The observation that there was not significantly higher decisional conflict in the low complexity group suggests that the information provided was seen to be as

sufficient to those participants as was the information presented to the high complexity group.

We hypothesized that higher communication complexity would lead to lower satisfaction in genetic counseling and lower perceived respect from the genetic counselor. However, those hypotheses were not supported. We also predicted that those in the higher complexity group would perform more poorly on the knowledge measure and that they would report being less engaged, which were also not supported. Participants generally had the same satisfaction, perceived respect, cancer genetics knowledge, emotional responses (besides negative emotion and confusion), engagement, and made the same testing decisions (and felt the same way about them), across the three communication complexity levels.

These findings were unexpected as research in medical and genetic counseling communication would suggest that lowering communication complexity and increasing interactivity would improve affective and cognitive outcomes. In one study in which subjects watched videos of simulated genetic counseling sessions from the GCVP and were told to imagine themselves as the client, individuals with restricted literacy (under the 8th grade level) benefited from and learned more in sessions with "greater dialogue interactivity and more personally contextualized information" (Roter et al., 2009). In the same study, they found that individuals with higher literacy did not see the same benefit, which is in line with our study's findings in our highly literate population. Studies in adult learning theory suggest that active learning and personal relevance benefit learning for all individuals, so we would have expected elements such as teach-back, using "you" statements, information chunking, and interactivity that engaged the participant to

enhance learning (Knowles, 2011; Doak et al., 1996). Our particular cohort was well-educated and had relatively high levels of genetic literacy, so we may not have been able to detect benefits of lowering complexity without a larger number of participants with lower literacy levels.

A study that assessed oral literacy demand in genetic counseling dialogue found that simulated clients were less satisfied with genetic counseling session communication when more technical terms were used, and dialogue was more dense and less interactive (Roter et al., 2007). The genetic counseling outcomes of satisfaction and respect have been traditionally high in genetic counseling outcome studies with real clients (Veach et al., 1999; Shiloh et al., 1990). However, although both outcomes were negatively skewed in our dataset, we had sufficient variability that we expected to see some differences across complexity levels. However, our study population was different in that they only received one session of genetic counseling, whereas the simulated clients in the Roter study experienced multiple sessions and were able to compare the sessions in ways that our participants could not.

As genetic testing and technologies continues to evolve, genetic counselors are also adapting their clinical practice, and there is evidence that cancer genetic counselors are moving to "[trade] depth of information for breadth" which may involve losing informational details (Hooker et al., 2017). In our study, those assigned to the lower complexity performed just as well, indicating that using more accessible language and more interactivity did not lead to lack of informed decision-making, frustration, or other negative outcomes in this group of relatively well-educated research participants. Of note, low communication complexity was not associated with decreased satisfaction with

care, perceived respect, positive emotional responses, knowledge, or increased decisional conflict. If genetic counselors are spending the majority of their time communicating genetics and biomedical information to their patients and clients, nothing appears to be objectively gained from providing that information in a complex way.

Relevance of Personal Characteristics

Regardless of communication complexity, participants' personal characteristics were associated with a number of our measured genetic counseling outcomes. In particular, the personal characteristics of genetic literacy, perceived personal cancer risk, and patient-provider orientation had significant relationships with the many of the measured outcomes. For decisional outcomes, older women and women who preferred more patient-centered interactions were slightly more likely to choose "No" over "Yes". This may have been due to a number of factors including being beyond reproductive age and living past much of the hypothetical risk of early-onset breast and ovarian cancer. Additionally, women with higher perceived personal risk for cancer were slightly more likely to choose "Maybe" over "Yes". Women with higher perceived personal risk of cancer also had higher decisional conflict, suggesting that their personal risk perceptions were impacting their test decisions as well as how they felt about that decision.

Emotional response was impacted by personal characteristics as well. Overall, older women tended to report feeling positive emotions after the session more strongly than did younger women. The qualitative data collected may provide context for this finding and whether older women felt that the session was more useful for themselves or their family members, or perhaps that they enjoyed the educational aspects of the videos,

or that they did not find the information particularly threatening to their own health. On the other hand, women with lower genetic literacy tended to report poorer emotional outcomes. They reported feeling positive emotions less strongly and also reported stronger negative emotional responses following the video genetic counseling session. This association between lower genetic literacy and poorer emotional response has been observed in the oncology setting in a study examining the link between emotional response and health literacy in women at risk for cervical cancer (Sharp et al., 2002).

Another participant group that felt less positively afterward viewing the sessions were women reporting a higher preference for patient-centered care. This finding may suggest that the hypothetical genetic counseling experience was not viewed as patient-centered due to absence of true two-way, adaptable communication. Though positive emotion is distinct from satisfaction, this finding is aligned with research that has shown that incongruence between the provider's patient-provider orientation and the patient's orientation can lead to patient dissatisfaction (Krupat et al., 2000). In the specific negative emotional response of "feeling different from others," non-Caucasian race was the only personal characteristic related to higher scores of feeling different, compared to Caucasian participants. Reasons for this could include elements of being presented with unfamiliar information by a genetic counselor of discordant race. However, race was not significantly negatively associated with the verisimilitude component "similarity to other healthcare," so non-Caucasian participants did not feel that the genetic counseling session was more dissimilar to care they had received in the past compared to the Caucasian women in the study.

After the video genetic counseling session, participants were given a cancer-genetics knowledge test. Genetic literacy and race were both related to knowledge scores. Individuals with lower genetic literacy tended to score more poorly on the knowledge measure. While the GLAC is a measure that approximates genetic literacy through assessment of familiarity with genetics certain terms, the cancer genetics knowledge measure is more specific to factual content that was introduced in the genetic counseling session that has been considered to be relevant to cancer genetic counseling. Though the GLAC and the knowledge test are separate measures, we expected the two be related as we would expect familiarity with genetics terminology to affect how readily one might gain new knowledge about cancer genetics. Beyond genetic literacy, individuals of Non-Caucasian race also performed more poorly on the knowledge test. In our cohort, the bivariate analysis showed that Non-Caucasian race was associated with lower GLAC scores as well as lower educational level and income, so the effects of race in this instance may be muddled by the group having lower genetic literacy overall. Of note, educational level was not found to be a significant predictor of cancer genetics knowledge, suggesting that genetic literacy and comfort with genetic-specific information were a better indicator of how well someone could learn from our genetic counseling sessions than educational level in our cohort.

Genetic counseling satisfaction was related to genetic literacy, patient-provider orientation, and the number of biological children. Having a lower genetic literacy was associated with lower satisfaction in the genetic counseling session, which was expected based on what is known about limited health literacy and lower satisfaction more generally in medical communication research (Jensen et al., 2010; MacLeod et al., 2017).

Individuals with higher PPOS scores were also less satisfied. Those with a preference for patient-centered style of care and communication may have not felt that their needs or expectations were fulfilled (as was observed in their less positive emotional responses), especially in this study context lacking true interaction. Interestingly, as the number of biological children increased, so did satisfaction. It is possible that this is related to women with more children finding the information to be useful for their children, beyond personal utility, leaving them to be more satisfied with the encounter. Open-ended answer data from our study may help elucidate specific opinions and feelings expressed by women with a higher number of children.

Interaction Effects between Complexity and Personal Characteristics

We also hypothesized that genetic literacy, patient-provider orientation, and personal perceived risk for cancer would moderate the effects of communication complexity on study outcomes. We found this to be true in the case of genetic literacy and patient-provider orientation, but not for perceived personal risk of cancer. There was a statistically significant relationship between genetic literacy and respect as well as genetic literacy and satisfaction in the high complexity condition but not in the medium or low complexity conditions. Individuals with lower genetic literacy tended to report lower satisfaction and lower perceived respect from the genetic counselor in the high complexity group. The genetic counseling satisfaction measure captures aspects of service quality which have short-term implications for care. Beyond the short-term effects, satisfaction has been suggested to related to the development of a therapeutic relationship and has been shown to enhance adherence to subsequent medical recommendations, both of which have implications for health outcomes (Street et al.,

2009; Ong et al., 2000). By capturing the short-term satisfaction, and by identifying instances in which satisfaction is reduced (or increased), interventions can be designed to not only improve satisfaction, but also to enhance health. Perceived respect from the genetic counselor can be viewed in a similar way and has similarly been associated in other medical contexts with longer term outcomes such as adherence (Beach et al., 2005). Individuals with lower literacy reported feeling less respected in the high complexity condition than did those with higher literacy. While our study detected effect modification of genetic literacy on complexity level for these two outcomes, a stronger effect might be detected in a cohort with more diversity in terms of genetic literacy, including individuals with much lower literacy levels.

Aside from satisfaction and respect, the effect of complexity level on knowledge was modified by the personal characteristic of patient-provider orientation such that a relationship was only observed in the medium complexity condition. In the medium complexity condition, as PPOS increased, so did knowledge scores. In this arm, individuals who preferred a more doctor-centered communication style demonstrated lower knowledge scores than those who preferred a patient-centered style. Individuals with lower PPOS scores prefer their providers to be the sole providers of information, to have less focus on emotional aspects of care and more on the problem or reason for medical visit, and to share more of the responsibility for decision-making in the session. The medium condition videos were designed to include as much factual detail as the high complexity, but using more plain language and utilizing more turn taking and interactivity. The medium complexity perhaps posed the greatest learning challenge through the combination of less accessible language presented in a non-preferred less

direct communication style. Perhaps the interactive aspects interfered with individuals' ability to take in the information presented. This pattern was not observed in either the high complexity nor the low complexity groups. Perhaps the more direct communication style in the high complexity condition (without much interaction) worked better when the information itself was highly complex and detailed for the subset of individuals who preferred a more doctor-centered approach. It is interesting to note that participants with similar preferences for doctor-centered communication did not have lower knowledge scores than others when assigned to a communication style that was more interactive when the information was also presented in a less complex manner, as in the low complexity condition. Again, analysis of the open-ended data collected will be useful in further characterizing and qualifying these patterns. Our participants had a range of PPOS scores, and gaining a better understanding of how PPOS contributes to learning within medical care will have important clinical implications. While there is evidence that discordance between patient and provider in PPOS can be detrimental to satisfaction, less is known about how discordance affects learning and longer-term health outcomes (Krupat et al., 2000).

Verisimilitude and Reported Engagement

Our study was unlike typical clinical genetic counseling care in several ways—it used a hypothetical scenario with analogue clients, involved video genetic counseling, was not truly interactive, and the genetic counselor did not adapt to verbal or mental responses from the participants. Verisimilitude scores for our study indicated that, despite these challenges, the majority (83%) of participants found it easy or very easy to play the role of the client and a slight majority (58%) found the genetic counselor to be realistic or

very realistic. The average score for similarity to other healthcare was between "somewhat similar" and "similar". This similarity score was not surprising as genetic counseling is a unique medical specialty in which a provider may explain many options and choices (including benefits and downsides), and often leaves the decision up to the client rather than instructing what should be done (in the absence of professional medical guidelines). The video aspect of the genetic counselor combined with the standardized nature of the interaction without feedback likely contributed to lower scores of verisimilitude, but despite these challenges, verisimilitude scores indicated this was a realistic experience for the participants across all three groups.

While the one-way nature of the video genetic counseling session was likely a barrier to engagement, it was encouraging to note that participants reported verbally or mentally engaging more often than not. As hypothesized, individuals with lower genetic literacy reported being less engaged with the video genetic counselor than those with higher genetic literacy. This pattern has been observed in other studies in which individuals with limited health literacy asked fewer questions and were less engaged in real healthcare settings (Doak et al., 1996). Though "engagement" in our study more closely resembled adhering to the requested tasks of the study (i.e. answering questions and responding), recording active engagement level and quality could be the target of further study, to determine how patient engagement varies when provider communication varies in complexity.

Participants who completed our study (N=286) invested time and energy into not only answering the survey questions, but also providing written responses to open-ended study questions. The relatively high scores in reality, ease, and reported engagement

suggest that this model of experimentation can be useful in gathering affective, cognitive, and written responses from participants, and that it can be a useful way of manipulating aspects of communication of information as well as individual aspects of communication such as empathic statements or elements of non-verbal communication that would be challenging or even impossible to study in the context of actual genetic counseling interactions.

Future Analysis

Beyond the quantitative results described, qualitative analysis of the open-ended answers gathered will provide context and depth. Though main effects of language complexity were not found with regard to most outcomes, additional insights may be gained from the qualitative data about how participants viewed the different experience. Additionally, any evidence of discordant answers between individuals in our cohort (i.e. one prefers to hear statistics whereas another finds statistics information least useful) would support the need for tailored communication of information in genetic counseling. Future analysis will aim to make connections between themes and concepts found in the open-ended questions and relate them to the quantitative data across complexity levels and different personal characteristics.

Limitations

By only focusing on manipulation of communication complexity, we did not capture elements of a genetic counseling appointment that involve the development of a therapeutic relationship. Providing education in the context of a therapeutic relationship

could have altered the observed effects., The nature of the relationship between client and genetic counselor can affect learning and knowledge outcomes as patients make meaning of the information they hear, (Street et al., 2009). Relationship building also involves building trust, and altering elements that impact the therapeutic relationship would also likely impact outcomes of satisfaction and perceived respect. We were not able to capture different approaches to teaching by involving visual aids or written material to reinforce what was being said by the genetic counselor. These learning aids, including graphs of risks, tables of gene names, and pictures of genetic material (DNA, genes, chromosomes) are often present in genetic counseling practice. Our participants may have been limited in what they were able to learn and remember by not seeing or reading media that emphasized the information presented by the genetic counselor.

Though our study utilized a unique experimental design that was able to standardize language and communication and reach many participants, it could not fully emulate an in-person or real-time genetic counseling session. Despite incorporating elements of interactivity and person-focused language, the video counseling was not able to tailor information to the participant. The video genetic counselor could neither skip over information that participants were already familiar with nor could she repeat, reframe, or slow down the information that she was communicating.

Another limitation was that our participant population was highly educated, highly familiar with genetics, and the majority were Caucasian. A brief overview of the open-ended data indicated that at least a few individuals noted that they worked in a medical or genetics field (as many CRVP participants are themselves NIH employees or trainees). There may have been a ceiling effect of genetic literacy present in this cohort.

We also had a large proportion of women past reproductive age who were older than the hypothetical client, which may have impacted the generalizability of the findings. However, older women did not report significantly lower levels of ease of playing the role of the client. Though our results indicate that most of the participants found it easy to imagine themselves as the client, decision-making under a personally threatening situation has been shown to impact learning and retention of information (Heilman et al., 2010), so more work will need to be done to characterize the effects we found in other settings and in the clinic.

Logistically, completing the study was designed to take 30-45 minutes, but some participants took over an hour, and comments in the open-ended questions indicated that there were too many videos and that it was hard to pay attention. Combined with the relatively low response completion rate, the study sample could be subject to bias. A shorter design with a narrower scope might make the study less tedious for participants, but the trade-off would likely mean only capturing a portion of genetic counseling communication, rather than attempting to capturing all of the communication of information a client might receive.

Clinical Implications

This study aimed to better understand how complexity of information communication impacts clients receiving genetic counseling in a hypothetical setting, drawing from adult learning theory and oral literacy demand principles as guides for emulating levels of high, medium, and low complexity experimentally. Though genetic counseling practice and communication of information is not standardized, the concept of

tailoring information in a way that is accessible to patient needs is universal in medicine and genetics. For our educated and genetic literate population, complexity did not have large main effects. In general, the outcomes of our study, including high levels of satisfaction and respect, and low levels of decisional conflict and negative emotional response mirror previous outcome studies of genetic counseling (Veach et al., 1999; Shiloh et al., 1990; Christie et al., 2012).

Our results support the notion that certain patient characteristics contribute to genetic counseling outcomes, and while those characteristics cannot be assumed to be deterministic, awareness of differential outcomes is important for clinical care. Unfamiliarity with genetics and low genetic literacy contribute to poorer genetic counseling outcomes, and extrapolating the trends of our findings, it would follow that patients with lower literacy levels than we observed would have poorer outcomes. Thus, evidence-based interventions designed for assessing and addressing genetic literacy to promote learning and understanding are warranted. Personal perceived risk for cancer (beyond reported family history of cancer) and patient-provider orientation also contribute to differential genetic counseling outcomes. Interventions designed to capture and address these concepts within or before the genetic counseling session could, in the context of adult learning theories, help promote more positive outcomes as well.

While genetics health professionals are well versed in the complex language of medical genetics, there is no obvious benefit in presenting information to patients in a complex way. While higher complexity language and genetics jargon may suit some patients who request additional detail or come into the appointment with a background in science and genetics, it may not be broadly successful, leaving patients with lower

literacy feeling less satisfied, less respected, and less engaged in their healthcare. Counselor-level interventions could benefit patient-provider communication by challenging counselors to practice and implement lower complexity language that is most relevant and useful for patients.

Future Research

While the impact of language complexity may not have been large in our cohort, research in more diverse populations is necessary, particularly in individuals with genetic literacy that is more representative of the general population. The interaction effects observed in our study suggest that complexity may have more profound implications for populations with more limited genetic literacy. The current study could be repeated, using the same video genetic counseling models, in a targeted population selected for lower literacy to better understand the impacts of complexity more broadly and to make comparisons with those with higher genetic literacy. Additionally, our cohort included only women and a hypothetical scenario. Emotional burden and stress can play into how individuals learn and make decisions (Heilman et al., 2010; Vogel et al., 2016), and there may be differences between hypothetical clients, unaffected individuals with an affected family member, and affected individuals. More research needs to be done on the impact of communication complexity in clinical populations, as well as in both men and women of all ages. Such a study would require experimentally manipulating genetic counseling practice style in actual healthcare contexts. Though our study only captured immediate post-counseling outcomes, more research is necessary to understand if and how

communication and short-term outcomes correlate with long-term outcomes including emotional well-being, adherence to medical recommendations, and health outcomes.

Other study designs could be used to test clinical interventions for genetic counselors that promote interactivity and turn taking, adult learning theories, and lowering oral literacy demand and subsequently measuring post-counseling clinical patient outcomes similar to those that were measured here. Another way of capturing the effects of complexity of communication of information could be to randomize genetic counseling patients to watch different levels of complexity of the same information prior to attending a genetic counseling session, and assessing the kinds of questions and quality of communication they have within the session after receiving a genetics lesson from the video. The video setup allows for easy manipulation of multiple aspects of communication, and many iterations and combinations of adjusting complexity components (i.e. teach back, turn taking, plain language, and information chunking) could be utilized to gain a more detailed understanding of the impact of specific changes in communication.

Communication of information is only one aspect of genetic counseling, though it is often the central component and the focus of genetic counseling sessions (Meiser et al., 2008; Roter et al., 2006). In our study, communication complexity did not affect most of our outcomes of interest. In addition to exploring other designs that might allow further understanding of the role of complexity, future research should also be done to examine if and which counseling aspects of genetic counseling (empathic statements, therapeutic relationship, values exploration, shared decision making, etc.) have an effect genetic counseling outcomes.

As the field of genetics continues to expand, more and more individuals will have access to genetic testing and genetic services. In order to adapt to the increase in demand, alternative service delivery models (including video or tele-counseling and education) is likely to become more widespread. Additional research will need to be done to assess how to best communicate information deemed important to the widest audience. Studies such as this one can help clarify how to promote learning and decision making in patients before those delivery models become more prevalent.

Conclusions

The results from our experimental video genetic counseling communication study suggest that though communication complexity did not have large main effects on genetic counseling outcomes in our study population (beyond reducing negative emotional response and confusion), participants assigned to lower complexity communication did not have outcomes that were significantly worse than those assigned to higher complexity communication. Personal characteristics, such as genetic literacy, patient-provider orientation, and perceived risk of cancer (among other demographic traits) were associated with differential decisional, affective, and cognitive outcomes as hypothesized based on previous work both within and outside of the genetic counseling context. In addition, the observed interaction effects underscore that language complexity may lead to differential outcomes among subsets of hypothetical genetic counseling clients. These differences reinforce the need for personally tailored communication as well as the need to implement targeted interventions to enhance communication, learning, and short- and long-term emotional and medical wellbeing. More research is needed in populations

representative of the patients that have genetic counseling to further characterize the effects of communication complexity and personal characteristics on outcomes to guide evidence-based genetic counseling clinical practice.

APPENDIX A: Study Recruitment Emails

CRVP Recruitment email: ResearchMatch Recruitment email:

Hello Potential Research Volunteer:

Previously, you contacted the **NIH Clinical Research Volunteer Program** (CRVP) for information about healthy volunteer studies. Because you gave permission to be in our volunteer pool, we want to make you aware of the following study that is actively recruiting:

Volunteers Needed

How do people respond to information about genetics?

Researchers at the National Institutes of Health (NIH) seek women volunteers, 18 years of age or older, who have no personal history of cancer (other than basal cell skin cancer) but do have a family history of cancer in a first or second degree relative to participate in a study researching how people respond to communication about genetic information.

Study Procedures Include:
- Collecting demographic information
- Viewing online videos
- Taking surveys
- Talking on the phone with a researcher about the study

Do you qualify?
- Are a woman age 18 or older
- Are fluent in reading and communicating in English
- Have at least one family member who has had cancer (excluding skin cancer)
- Family member cannot be a sister who has had breast cancer
- Have no personal history of cancer (excluding basal cell skin cancer)
- Have access to a computer with an internet connection
- Have never had genetic counseling

Location: This study will be conducted through a secure website and over the phone, and participation in the study will not require travel to the NIH campus.

Compensation: Participants will be compensated with a $10 Amazon gift card after completion of the study.

If you are interested in participating: Please contact emily.bonkowski@nih.gov to set up a time to complete the study.

OR (alternative email with link):
If you are interested in participating: Please proceed to the following link to proceed:
http://jhsph.co1.qualtrics.com/jfe/form/SV_byAQp9fQmjYuFNz

ResearchMatch Recruitment email:

Hello Potential Research Volunteer:

Previously, you contacted ResearchMatch for information about volunteer studies. Because you gave permission to be in this volunteer pool, we want to make you aware of the following study that is actively recruiting:

Volunteers Needed

How do people respond to information about genetics?

Researchers at the National Institutes of Health (NIH) and Johns Hopkins University seek women volunteers, 18 years of age or older, who have no personal history of cancer (other than basal cell skin cancer) but do have a family history of cancer in a first or second degree relative to participate in a study researching how people respond to communication about genetic information.

Study Procedures Include:
- Collecting demographic information
- Viewing online videos
- Taking surveys

Do you qualify?
- Are a woman age 18 or older
- Are fluent in reading and communicating in English
- Have at least one family member who has had cancer (excluding skin cancer)
- Family member cannot be a sister who has had breast cancer
- Have no personal history of cancer (excluding basal cell skin cancer)
- Have access to a computer with an internet connection
- Have never had genetic counseling

Location: This study will be conducted through a secure website, and participation in the study will **not** require travel.

Compensation: Participants will be compensated with a $10 Amazon gift card a few days after completion of the study.

If you have already participated in this study, you will not be eligible to participate again.

Questions: Please do not reply to this email, but contact Emily Bonkowski directly at emily.bonkowski@nih.gov if you have any questions about participation.

ResearchMatch email containing link to the study:

Hello,

Thank you for your interest in our study about the communication of genetic information. If you are still interested in participating, please follow the link below to proceed:

http://jhsph.co1.qualtrics.com/jfe/form/SV_byAQp9fQmjYuFNz

The study is set up to be done entirely on the website above, and requires access to a computer with video and audio capabilities. The study should take about 30-45 minutes to finish.

Compensation will be a $10 Amazon gift card emailed to you a few days after completion of the study.

Thank you,
Emily
--
Emily Bonkowski
ScM Candidate in Genetic Counseling ‘18
Johns Hopkins University/National Human Genome Research Institute
emily.bonkowski@nih.gov

APPENDIX B: Online Informed Consent Form

Thesis Survey (Qualtrics form)

Start of Block: Consent

You are invited to participate in a study conducted by researchers at the National Human Genome Research Institute and Johns Hopkins University Bloomberg School of Public Health.

What is the purpose of this study? To learn about how people prefer to receive information in the context of genetic counseling.

Why am I being invited to be in this study? We are interested in learning from women of all backgrounds. You can take part in this study if you are at least 18 years old, have no personal history of cancer (other than basal cell skin cancer), have had one family member diagnosed with cancer (you cannot have a sister who has had breast cancer), and are fluent in reading and communicating in English.

What is involved in this study? You will be asked to watch videos and answer survey questions. This study will consist of online web-based modules that simulate a specific portion of a genetic counseling session. Through the website, you will first be asked a few questions about your background, as well as some general questions about genetics, your family and personal health history, and questions about how you prefer to communicate. The total time to complete this study is 30-45 minutes.

What are the risks of this study? There are no physical risks of taking part in this study. However, it is possible that some questions may bring up uncomfortable emotions. If completing the study makes you feel upset or uncomfortable, you can stop the study at any time. If you feel upset after completing the survey, you can contact the researcher (contact information provided below).

Please keep in mind that the information you hear as part of the web-based exercises is not information related to your own personal and family health history and won't apply to you directly. If you have questions about your own personal or family health history, you should see a genetic counselor or other health professional.

Are there benefits to taking part in the study? You will not directly benefit from participating. However, you will help us better understand how to communicate genetic information and may help inform changes in the way health information is communicated in the future.

Do I have to take part? Participation in the study is optional. If you begin the study, you can stop it at any time. You can choose to skip survey questions that you do not wish to answer. Choosing not to participate will have no impact on the health services you receive or other research participation you may be involved in now or in the future.

Who else will know that I am in the study? We do not ask for your name anywhere in this study. If you provide us with a name or other identifying details, we will not link your name with your responses. Your answers will not be a part of any medical record, and your personal information will not be identifiable when we report our research results. Only the researchers involved in analyzing and interpreting the study data will have access to your responses, but even they will not be able to link your responses to your name.

Will I receive payment for being in this study? There will be a payment of a $10 Amazon gift card for completion of the study. Once your survey is submitted, you will be provided with an email address to contact for your payment. Your email address will be used to send the gift card electronically. Your email address will not be linked to your survey responses.

How do I take part? Please follow the link to the online web-based tool, and follow the instructions for completion of the study. Access to a computer with audio capabilities and internet access and is required.

Will I be told about the findings of the study? If you would like to be contacted about the results of the study, please complete the contact information form at the end of the survey. This contact information will not be linked to your study responses. We will not share your contact information with anyone outside of the research team or use it for any reason besides giving you the overall results of the study.

Problems or questions? If you have problems or questions regarding the study or your rights as a participant, please contact the researchers (contact information provided below).

Researchers' Contact Information:

Emily Bonkowski
Co-Investigator
Genetic Counseling Graduate Student
JHU/NHGRI Genetic Counseling Program
emily.bonkowski@nih.gov

Lori Erby, PhD, CGC
Principal Investigator
JHU/NHGRI Genetic Counseling Training Program
lori.erby@nih.gov

End of Block: Consent

APPENDIX C: Study Instrument

Q77 Thank you for agreeing to participate in our study. Please confirm that you are eligible for the study by confirming that the following statements are all true:

I am a woman over the age of 18.
I can fluently read and communicate in English.
Someone in my family has had cancer.
I have never had cancer (except basal cell skin cancer).
I do not have a sister who has had breast or ovarian cancer.
I have never had genetic counseling.

- ○ Yes, all statements are true for me.
- ○ No, one or more of the statements are NOT true for me

Q78 Please certify that you are a human.

End of Block: Consent Digital/Human Verification

Start of Block: Demographics

Q3 What is your age?

_____

Q4 What is your racial background?

- ○ Caucasian
- ○ African American
- ○ Asian or Pacific Islander
- ○ American Indian or Alaska Native
- ○ Other
- ○ Identify as more than one

Q5 What is your ethnic background?

- ○ Hispanic or Latina
- ○ Non-Hispanic or Latina

Q6 What is the highest degree or level of education you have completed?

- ○ Less than high school
- ○ High school graduate (includes High School equivalency)
- ○ Some college, no degree
- ○ Associate's degree
- ○ Bachelor's degree
- ○ Graduate or professional degree

Q7 What is your annual household income?

- ○ Under $25,000
- ○ $25,000-50,000
- ○ $50,000-75,000
- ○ $75,000-100,000
- ○ Above $100,000

Q8 What is your marital status?

- ○ Single
- ○ Married
- ○ Divorced
- ○ Widowed
- ○ Other _____

Q9 How many biological children do you have?

▼ 0 … 10+ (11)

End of Block: Demographics

Start of Block: Family History

Q17 Please select the appropriate number for how many of the listed female relatives have had cancer in your family.

Some numbers may not apply to the family member.

	Breast and/or Ovarian Cancer					Other Cancer(s)				
	0	1	2	3 or more	N/A	0	1	2	3 or more	N/A
Mother	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Sister(s)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Daughter(s)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Grandmother(s)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Aunt(s)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Niece(s)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Female cousin(s)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Other (8)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Q131 Please select the appropriate number for how many of the listed male relatives have had cancer in your family.

Some numbers may not apply to the family member.

	Male Breast Cancer					Prostate Cancer					Other Cancer(s)				
	0	1	2	3 or more	N/A	0	1	2	3 or more	N/A	0	1	2	3 or more	N/A
Father	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Brother(s)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Son(s)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Grandfather (s)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Uncle(s)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Nephew(s)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Male cousin(s)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Other (8)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Q24 What do you think is your risk of getting cancer?

- Much lower than average
- Lower than average
- About the same as average
- Higher than average
- Much higher than average

End of Block: Family History

Start of Block: GLAC

Q26 The words below are words that patients in the genetics clinic sometimes struggle with. The first question after the word asks how familiar you are with each word. Marking "1" on the scale reflects that you strongly disagree, marking "7" on the scale means that you strongly agree. Please circle the number that best reflects your opinion. The second question asks you to choose the best word which fills in the blanks.

Q27 **Genetic**

I am familiar with this term

- Strongly disagree 1
- 2
- 3
- 4
- 5
- 6
- Strongly agree 7

Q28 Genetics is the study of how living things receive common traits from previous _____.

- ○ generations
- ○ experiences
- ○ exposures
- ○ germinations

Q29
Chromosome

I am familiar with this term

- ○ Strongly disagree 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ Strongly agree 7

Q30 A chromosome contains all of our _____ material.

- genetic
- digestive
- cellular
- brain

Q31 **Susceptibility**

I am familiar with this term

- Strongly disagree 1
- 2
- 3
- 4
- 5
- 6
- Strongly agree 7

Q32 Susceptibility to a disease means you _____ get the disease.

- eventually will
- definitely
- might
- will never

Q33 **Mutation**

I am familiar with this term

- Strongly disagree 1
- 2
- 3
- 4
- 5
- 6
- Strongly agree 7

Q34 A mutation is a change in your _____.

- intestine
- skin
- DNA
- blood

Q35 **Variation**

I am familiar with this term

- ○ Strongly disagree 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ Strongly agree 7

Q36 Having variation in the genetic code will lead to disease _____.

- ○ all of the time
- ○ some of the time
- ○ never
- ○ only in animals

Q37 **Abnormality**

I am familiar with this term

- ○ Strongly disagree 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ Strongly agree 7

Q38 _____ is an abnormality.

- A trachea
- Brown hair
- Trisomy
- Blood pressure

Q39 **Heredity**

I am familiar with this term

- Strongly disagree1
- 2
- 3
- 4
- 5
- 6
- Strongly agree7

Q40 Heredity is the transfer of characteristics from _____.

- the environment to the person
- the sick to the healthy
- parent to child
- teacher to student

Q41 **Sporadic**

I am familiar with this term

- ○ Strongly disagree1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ Strongly agree7

Q42 A genetic disease that occurs without _____ is considered sporadic.

- ○ symptoms
- ○ a family history
- ○ a diagnosis
- ○ medication

End of Block: GLAC

Start of Block: PPOS

Q43 Please select how strongly you agree or disagree with each of the following statements:

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
The health care provider is the one who should decide what gets talked about during a visit.	○	○	○	○	○	○	○
Although health care is less personal these days, this is a small price to pay for medical advances.	○	○	○	○	○	○	○
The most important part of the standard medical visit is the physical exam.	○	○	○	○	○	○	○
It is often best for patients if they do not have a full explanation of their medical condition.	○	○	○	○	○	○	○
Patients should rely on their health care providers' knowledge and not try to find out about their conditions on their own.	○	○	○	○	○	○	○
When health care providers ask a lot of questions about a patient's background, they are prying too much into personal matters.	○	○	○	○	○	○	○
If health care providers are truly good at diagnosis and treatment, the way they relate to patients is not that important.	○	○	○	○	○	○	○
Many patients continue asking questions even though they are not learning anything new. (8)	○	○	○	○	○	○	○
Patients should be treated as if they were partners with the health care provider, equal in power and status. (9)	○	○	○	○	○	○	○

Q44 Please select how strongly you agree or disagree with each of the following statements:

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
Patients generally want reassurance rather than information about their health.	○	○	○	○	○	○	○
If a health care provider's primary tools are being open and warm, the health care provider will not have a lot of success.	○	○	○	○	○	○	○
When patients disagree with their health care provider, this is a sign that the doctor does not have the patient's respect and trust.	○	○	○	○	○	○	○
A treatment plan cannot succeed if it is in conflict with a patient's lifestyle or values.	○	○	○	○	○	○	○
Most patients want to get in and out of the health care provider's office as quickly as possible.	○	○	○	○	○	○	○
The patient must always be aware that the health care provider is in charge.	○	○	○	○	○	○	○
It is not that important to know a patient's culture and background in order to treat the person's illness.	○	○	○	○	○	○	○
Humor is a major ingredient in the health care provider's treatment of the patient. (8)	○	○	○	○	○	○	○
When patients look up medical information on their own, this usually confuses more than it helps. (9)	○	○	○	○	○	○	○

End of Block: PPOS

Start of Block: Scenario

Q73 Please consider the following hypothetical scenario:
Imagine that you have a sister and that she was recently diagnosed with invasive breast cancer at the age of 39. She suggested that you meet with a genetic counselor about your risk for breast cancer, and an optional genetic test that could be available to you if you were interested. Today, you'll be watching videos that represent what genetic counseling sessions might look like, and you'll be asked a series of questions about your thoughts, feelings, and experiences overall after viewing the videos.
The genetic counselor may also ask you questions during the session. While we won't be recording your responses to those questions, in order to enhance the reality of the videos, please respond when the genetic counselor poses a question (out loud or in your head). Please answer the questions as if this were a real situation, but also remember that this in no way reflects your actual personal risk for breast and ovarian cancers.

For this part of the study, you will watch 10-15 short video clips and then answer questions about what you saw.

[***See Appendix D for video scripts***]

Start of Block: Test Yes/No

Q45 If you were the client seeing this genetic counselor, would you want to have genetic testing today?

- ○ Yes
- ○ Maybe
- ○ No

End of Block: Test Yes/No

Start of Block: Emotional Response, Decisional Conflict

Q47 If you were the person seeing this genetic counselor, how much of the following emotions do you imagine you might feel after the session ended? Marking “7” on the scale means that you feel that particular emotion very much, and marking “1” means that emotion not at all. Please select the number that best reflects your emotion.

	None 1	2	3	Somewhat 4	5	6	Very Much 7
Fear	○	○	○	○	○	○	○
Ease of Mind	○	○	○	○	○	○	○
Confusion	○	○	○	○	○	○	○
Confidence	○	○	○	○	○	○	○
Frustration	○	○	○	○	○	○	○
Different from Others	○	○	○	○	○	○	○

Q48 Please select how strongly you agree or disagree with each of the following statements regarding your decision to proceed with genetic testing:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
This decision is easy for me to make.	○	○	○	○	○
I'm unsure what to do in this decision.	○	○	○	○	○
It's clear what choice is best for me.	○	○	○	○	○
I'm aware of the choices I have.	○	○	○	○	○
I feel I know the benefits of my decision.	○	○	○	○	○
I feel like I know the side effects of my decision.	○	○	○	○	○
I know how important the benefits are to me in this decision	○	○	○	○	○
I know how important the risks and side effects are to me in this decision (8)	○	○	○	○	○
It's hard to decide if the benefits are more important to me than the risks, or if the risks are more important than the benefit (9)	○	○	○	○	○
I feel pressure from others in making this decision (10)	○	○	○	○	○

I have the right amount of support from others in making this choice (11)	○	○	○	○	○
I need more advice and information about the choice (12)	○	○	○	○	○
I feel I have made an informed choice (13)	○	○	○	○	○
My decision shows what is important to me (14)	○	○	○	○	○
I expect to stick with my decision (15)	○	○	○	○	○
I am satisfied with my decision (16)	○	○	○	○	○

End of Block: Emotional Response, Decisional Conflict

Start of Block: Open Ended 1

Q49 If this were a real situation, who would you share this information with? (select all that apply)

☐ Physician

☐ Family

☐ Friends

☐ Other _____

Q50 If you had to explain in a few sentences what you learned from this session to someone you know, what would you say?

_____

_____

_____

_____

_____

End of Block: Open Ended 1

Start of Block: Respect, Satisfaction

Q51 Please select how strongly you agree or disagree with the following statement imagining that you were the patient:

My genetic counselor has a great deal of respect for me.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Q52 *Please read each statement below carefully and tell us how much you agree with each statement by selecting the number that describes how much you agree or disagree if you were the client seeing the genetic counselor.*

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
My genetic counselor seemed to understand the stresses I was facing.	○	○	○	○	○
My genetic counselor helped me to identify what I needed to know to make decisions about what should happen to me.	○	○	○	○	○
I felt better about my health after meeting with my genetic counselor.	○	○	○	○	○
The genetic counseling session was about the right length of time I needed.	○	○	○	○	○
My genetic counselor was truly concerned about my well-being.	○	○	○	○	○
The genetic counseling session was valuable to me.	○	○	○	○	○

End of Block: Respect, Satisfaction

Start of Block: Open Ended 2

Q53 In the session, is there anything you wish you would have been able to ask?

○ Yes

○ No

Q54 If yes, what do you wish you would have been able to ask?

_____

_____

_____

_____

_____

Q55 In the session, is there anything you wish you would have been able to say?

- Yes
- No

Q56 If yes, what do you wish you would have been able to say?

_____

_____

_____

_____

_____

End of Block: Open Ended 2

Start of Block: Knowledge

Q57 Please answer True or False to the following questions:

	True	False
Early-onset breast cancer is less likely due to an altered BRCA gene than is late-onset breast cancer.	○	○
A woman who has a sister with an altered BRCA gene has a 50% risk of having an altered gene herself.	○	○
A woman who has her breasts removed can still get breast cancer.	○	○
A father can pass down an altered BRCA gene to his children.	○	○
One in 10 women have an altered BRCA gene.	○	○
There are many different genes that cause cancer.	○	○
One half of breast cancer cases occur in women who have an altered BRCA gene.	○	○
Tests for ovarian cancer often do not detect a tumor until it has spread. (8)	○	○
All women who have an altered BRCA gene will get cancer. (9)	○	○
A woman who does not have an altered BRCA gene can still get breast or ovarian cancer. (10)	○	○
Having ovaries removed will definitely prevent ovarian cancer. (11)	○	○

End of Block: Knowledge

Start of Block: Open ended 3

Q58 What information was **most** important to you from what you heard?

_____

_____

_____

_____

_____

Q59 What information was **least** important to you from what you heard?

_____

_____

_____

_____

_____

Q60 How did the information influence the decision you made?

_____

_____

_____

_____

_____

Q61 What was easy to understand in the session?

_____

_____

_____

_____

Q62 What was confusing in the session?

_____

_____

_____

_____

_____

Q63 What else do you wish you would have learned from the genetic counselor?

_____

_____

_____

_____

_____

End of Block: Open ended 3

Start of Block: Verisimilitude

Q65 Please select the best answer that represents how you feel for each statement:

Q66 How easy was it for you to take on the patient role when viewing the video genetic counselor?

- Very difficult
- Hard
- Easy
- Very easy

Q67 How real did the genetic counselor in the video seem?

- Not at all real
- Somewhat real
- Real
- Very real

Q68 How similar was the genetic counselor to health care you have received in the past?

- Not at all similar
- Somewhat similar
- Similar
- Very similar

End of Block: Verisimilitude

Start of Block: Answering questions, integrity

Q69 When the genetic counselor asked you a question, how often did you answer the question (out loud or in your head)?

- Not at all
- Some of the time
- About half of the time
- Most of the time
- All of the time

Q70 The integrity of our research data is important to us. Have you answered the survey questions honestly? You will be compensated regardless of your answer, and your answer will not be linked to your email address or personal information.

- Yes
- No

Q103 Is there anything else you would like the researchers to know?

_____

_____

_____

_____

_____

End of Block: Answering questions, integrity

Start of Block: Thank you

Q71 Thank you for participating in our study. We would like you to keep in mind that this study is hypothetical and in no way reflects your personal risk for cancer. If you would like to meet with a genetic counselor, please visit NSGC.org and click on "*Find a Genetic Counselor*" to locate one in your area. If you would like to contact the researchers about questions or concerns, please refer to the contact information provided below.

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On the next page, you will be taken to a new website where you can enter your email address to receive compensation for the study. The electronic Amazon gift card code will be emailed to you within a few days. Your personal contact information will not be linked to the answers you gave or your study data in any way.

APPENDIX D: Video Genetic Counseling Scripts

HIGH COMPLEXITY

Hello, my name is Mary, and I'm a genetic counselor. I've taken a look through your records and have a good idea of what brings you in today. We'll be talking about your sister's recent diagnosis of breast cancer and how, from a genetic standpoint, we might think about your situation.

I have a plan for what I think might be helpful for us to talk about in our time together, but I was wondering if you could tell me in your own words what brings you in today, and if you have any questions before we get started?

Thanks, it's helpful to know where you're coming from, and I hope I'll be able to answer most of those questions. So, today, we'll review what we know about the genetics of cancer, particularly breast cancer and related cancer syndromes. We'll also talk about how they track in certain high-risk families. Then, we can talk more about the genetic testing that we have available, and what kinds of results we can get from a genetic test. If you decide to have testing, depending on the results of the test, there may be specific recommendations that we would make for you and other family members. This would include breast and ovarian cancer surveillance, treatment, and potential consideration of prophylactic surgeries to reduce the risk of cancer for you if the test comes back positive.

So, let's review what we know about the inheritance of breast and ovarian cancer syndromes and breast cancer in general. We'll also go over some basic genetics concepts.

When we think about who develops cancer, we know that most cancer is sporadic, and we don't have a known cause of that cancer. Cancer is multifactorial. That means that it can be caused by multiple different factors, including a mixture of environmental, lifestyle, and genetic contributors.

We know that only 5-10% of cancer is hereditary. Of those hereditary cancers, there are a small proportion that have a genetic cause that we can identify today. Hereditary cancers are more likely to have individuals with younger onset cancer, multiple generations of family members affected, and multiple related cancers--such as breast and ovarian--in the same family.

Okay?

If we think about genetics, from high school biology you might remember that every part of our body is made up of thousands and thousands of cells. And in every cell of our body there are structures called chromosomes. Chromosomes package our genetic material together. We have 46 chromosomes in every cell of our body. They come in pairs, and are numbered by size from one to 22. The first 22 pairs are exactly the same in both men and women, and you get one half of each pair from your mother and the other half from your father. The last pair is the sex chromosomes. Women are XX and males are XY. When you have a child, you pass on one from each set. The child then has 50% of his or her chromosomes from the father and 50% from the mother.

On each chromosome, there are hundreds to thousands of genes. Normally, everyone has two copies of each gene, one copy from each parent. Those genes are made up of DNA. The DNA bases code for amino acids, which code for proteins. Proteins have a variety of functions within the body. Essentially, the genes we have are the instructions that tell our body how to develop, grow, and function. This includes things like determining our eye color and how curly our hair is.

Do you have any questions?

We know that there are certain genes that function to help prevent cancer. These genes come in a few different types, including tumor suppressor genes, oncogenes, and DNA repair genes that work to detect errors in the way that cells are proliferating. Several genes scientists have discovered confer a higher risk for developing breast cancer when something in the spelling of the gene is wrong or mutated. For instance, some studies have shown that women who have a variant, in one of these genes might have a lifetime risk of up to 80-85% of developing breast cancer, and up to 40% risk of developing ovarian cancer. In the general population, the lifetime risk for breast cancer is 12% in women. The lifetime risk for ovarian cancer is about 1-2% in women.

From researching many families with more cancer than average, we have discovered a few genes that predispose individuals to developing cancer in their lifetimes. The first two breast cancer genes, BRCA1 and BRCA2, were first discovered in the 1990s by studying families with a lot of women who were getting cancer at young ages.

Have you heard of BRCA1 and BRCA2 before today?

Okay. Since that time, many women with early onset breast and ovarian cancers have been genetically tested. We now have a better idea of which gene variants confer a predisposition to cancer.

Often, people with variants in these genes will develop cancer at an earlier age, under the age of 50, or the cancer will have a specific pathology. For example women with cancer due to a BRCA1 variant are more likely to have triple negative breast cancer compared to the women who have sporadic cancer that isn't due to a BRCA1 variant.

Now, the variants that I'm talking about can happen in two ways. The first way is that a variant can come through the germline. This means you inherited it from one of your parents and that it was present in the sperm cell or the egg cell at conception. In this case, the variant is present in all of the cells in the body. The second way a variant can occur in the body is that it can be acquired in a single cell at some point in a person's life.

Okay?

In order for cancer to develop, two variants actually need to be present. First in one copy of that gene, then in the other copy of that gene, so that there are no working copies. They call this the two hit hypothesis. We now know it's more than a hypothesis. When these genes don't work, cells can grow out of control, which turn into cancer and tumors in the tissue.

When there's one copy of a gene that has a variant, that makes someone a carrier. Being a carrier, or having a germline variant means that that person has a predisposition to cancer. It's not a guarantee that the person will develop cancer. There is still one functioning copy, but a second hit or a second variant in the other copy of the gene can happen. Then there are no working copies of the gene. When that happens cancer is more likely to occur.

Do you have any questions about any of that?

After our visit, I will send you a letter that has the main points of what we talked about today, so hopefully that will also help to answer your questions.

I'd now like to go over what testing we could offer you. When we test individuals for genetic changes that predispose someone to cancer, it's usually best to test a person who has been affected with cancer first. That way, if the test is positive, we know what is causing the cancer in that person and what test should be offered to the rest of the family. If it's negative, we know that there isn't an identifiable genetic cause for the cancer at this time. We would know that we wouldn't be able to test additional family members. If the affected person tests negative, that wouldn't necessarily mean that there isn't something genetic or inherited that is causing the cancer. It could mean that we haven't discovered the gene yet. Or, it could mean that the cancer was caused by something else. A negative test can be difficult to interpret.

If we were to test you today without testing someone in the family who has had cancer, if it were positive, we would say that you are at a higher risk to develop cancer. If we tested you today and you were negative, you would be an uninformative negative. That would mean that we wouldn't be able to tell if you were truly negative and didn't inherit what genetic variant is causing the cancer in your sister, or if you are negative because if we tested your sister, we wouldn't have found anything, so we wouldn't have found anything in you anyway. I see that your sister isn't interested in getting tested, and maybe that's something that you could talk to her about later, after her cancer treatment is over. We are still able to test you, even though it might be harder to interpret your results and what they would mean for your genetic risk for cancer. Having a first degree relative affected with breast cancer (your sister) increases your risk for developing cancer yourself regardless of genetic testing. We'd like you to be diligent about your mammograms and regular cancer screenings no matter what genetic testing might tell us.

Does that make sense?

The test we would offer you today is a cancer panel test which looks for variants or changes in ten genes we know are associated with the development of breast cancers. Variants in these genes can also indicate that you are at an increased risk for other types of cancers, including ovarian, pancreatic, thyroid, prostate cancer in men, and melanoma, among others. The test uses sequencing technology and quantitative methods to look for changes in the gene, such as spelling errors or extra or missing pieces, such as insertions, duplications, or deletions. These ten genes have been grouped together onto one test, because for each of these ten genes, there are professional guidelines for how to change medical management based on finding a variant. There may be screening protocols or

surgical options to consider.

The first two genes on the panel we know more about, BRCA1 and BRCA2, which I mentioned earlier, and variants in both of these genes predispose you to develop breast and ovarian cancers. The risk for breast cancer for people with pathogenic variants in BRCA1 or BRCA2 is as high as 80-85% by age 70. The ovarian cancer risk in BRCA1 is 39% by age 70, and for BRCA2 it's 11-17% by age 70. As we talked about earlier, these risks are substantially higher than for women who do not have variants in BRCA1 or BRCA2. For women without variants in BRCA1 or 2, the lifetime risk for breast cancer is about 12% and the lifetime risk for ovarian cancer is about 1-2% in women.

The other genes we are looking at are genes that have been reported in the literature as being associated with breast cancer, but may have a lower penetrance. This means that the risk for cancer would not be as high. As I mentioned, a few of them are associated with other types of cancer--ovarian, pancreatic, thyroid, prostate, melanoma--and there would be specific recommendations we would make for you based on what the genetic test tells us. There might be some screening or imaging tests we would recommend to detect any development of cancer in those areas. Unfortunately, for some kinds of cancer, including ovarian cancer and pancreatic cancer, there are no medically sensitive tests that can reliably detect early stage cancers.

The genetic test that we can offer won't be able to tell you when you will get cancer, or even if you will get cancer. None of the genes come with a 100% certainty that someone will get cancer if they have a variant in that gene. The uncertainty about whether or not you get cancer could potentially cause some worry and anxiety. It's important to think about what this test would mean for you.

So, from doing this genetic test, there can be three outcomes: a positive test result, a negative test result, or an uncertain test result.

The first outcome could be that the test is positive. This would mean that we have found a pathogenic variant in your DNA that predisposes you to developing breast cancer, and potentially other cancers in your lifetime.

If the test is positive, there would be specific medical recommendations and medical decisions for you to think about.

In that case, the first important thing to think about would be breast cancer screening and surveillance. With a positive test, the professional guidelines recommend breast mammography and breast MRI done every six months, alternating, for early detection if breast cancer develops. The MRI is an additional method of imaging the breast tissue. It can be useful in detecting cancer in younger women as well as in women who have dense breast tissue.

Another thing to think about is that if you do develop breast cancer at some point in your life, having a positive genetic test result would increase your risk for having an additional primary cancer in a brand new spot in your breast or in the other breast. Some women choose to have a prophylactic mastectomy to remove both breasts as a preventative measure. Removing the breast tissue greatly reduces the risk for breast cancer, but

doesn't reduce it all the way to zero. There may be a few breast tissue cells left over after surgery. Clinical breast exams of the chest wall would be a good way to continue to do breast screening after a double mastectomy. In women who choose this, many also choose to do reconstructive surgery at the same time. Some women choose to have a preventative mastectomy so that they do not have to do the intensive screening of mammography and MRI every 6 months.

In the case of breast cancer, a lumpectomy could also be an option, to just remove the cancerous cells. You would then continue doing screening to detect any recurrence or new primary cancer in the remaining breast tissue.

While the risk for breast cancer is one of our priorities, variants in some of these genes, like BRCA1 and BRCA2 can increase a woman's risk for ovarian cancer. So, the second thing to think about, in the case that the genetic test is positive for a variant in a gene that also increases risk for ovarian cancer would be to consider the surgical removal of the ovaries and the fallopian tubes. Unlike breast tissue, the ovaries and fallopian tubes (which can also develop cancer) are harder to access. The current screening methods we have, including PAP smears, testing hormone levels like CA125, and ultrasounds aren't particularly sensitive. If those tests pick up cancer it is often at a later stage. Because of this, we would recommend the removal of your ovaries after you are done having children, by your late thirties or early 40s. Removing the ovaries not only greatly reduces the risk for ovarian cancer by about 96%, but it also reduces the risk for breast cancer by about 50%. However, removing the ovaries forces the body to go into premature menopause. This may not be ideal or comfortable, and you can talk to your doctor about how you might manage the symptoms of menopause.

Also, if you were to test positive, we could begin offering genetic testing to your other family members who are at risk. Because these variants are usually passed on from generation to generation, and inherited from a mother or father, we know that your first degree relatives would have a 50% risk, like the flip of a coin, of having the same variant. Both men and women can pass on these variants. This would include your siblings, parents, and children. Extended family members could also be at risk.

The test result would have implications for men in your family as well. While breast cancer is more common in females, it can also happen in males, and males who carry a BRCA variant are at a higher risk of developing male breast cancer as well as at an increased risk for developing prostate cancer.

You may have questions about testing children in the family. We don't recommend testing children under the age of 18, as there are no known associations with childhood cancer in most of the genes we are testing. We recommend waiting until at least 18 so that they are able to make that decision for themselves. Even at 18, individuals might not want to or feel ready to do genetic testing.

Overall, you should know that if the test comes back positive, we would make a plan for how to move forward for you and your family, to help prevent and detect cancer in the future.

The second possible result could be a negative result. For you, this would mean that we did not find any variants in the genes we looked at that we know are most highly associated with an increased risk of developing breast and related cancers. As we talked about earlier, this does not necessarily rule out the possibility that there is an inherited cancer running in your family. You would still be at increased risk above the general population given your family history of breast cancer at an early age in your sister. However, we can have some reassurance that we did not find any variants in the genes we looked at, including the highest risk BRCA1 and BRCA2 genes.

If you get a negative result, we would still want you to be vigilant about getting screened for breast cancer because of your family history. You should talk to your doctor about coming in earlier than you might usually be recommended to, to get mammograms. This would be the case even if you decide not to get testing at all. If your sister were ever to get tested, and she *did* end up testing positive, we would then know that you did not inherit the same variant that she has from one of your parents. This would mean you and your children would not be at a higher risk to develop cancer than the general population. Without her results, as I mentioned earlier, we would still be left not knowing whether or not our testing would have detected the cause of cancer in your family.

The third type of test result is a variant of uncertain significance. This would mean that we found something in one or more of the genes that we tested you for, but that we aren't sure if it is benign and doesn't increase risk for cancer or pathogenic and does increase risk for cancer. Over time, laboratories continue to do research, and continue to test people with and without cancer to determine which genetic variants are associated with cancer and which ones are just common variation in the population. We all have genetic differences and variation, so this is a case where knowing more about normal human variation can help us learn more. As the lab collects more information, it is possible that they will reclassify the variant as either benign or pathogenic. They will contact us if and when that happens, and we will pass the information on to you so that you can incorporate that information into your own medical management. If your test result has an uncertain variant, we would not recommend that you change your medical care, but that you should continue to get regular cancer screenings.

That was a lot of information, do you have any questions about what I just went over about the three kinds of results?

One last thing we like to tell our patients about is something called the Genetic Information Nondiscrimination Act or GINA. Whenever someone has genetic testing done, that genetic information and the test result are placed in the medical record. There is a law that protects individuals from being discriminated against based on their genetic information. This protects discrimination in employment and health insurance. The areas that GINA does not cover are long-term care, life insurance, and disability coverage. Currently, insurance agencies are allowed to ask for your information, and could make a policy decision based on that. For this reason, some people like to have their plans in place before proceeding with genetic testing. Current policies would not be affected, but if you were to apply in the future, those types of insurers would be allowed to ask for genetic information. In my experience, this hasn't been a major issue or problem for anyone, but it is something to consider.

Okay?

So, after our discussion today, if you think this testing is something you'd like to do, we could do the test today. You can also go home to think about it or decide not to do testing at all at this point, knowing that you can always revisit the issue later. Logistically, it would be a simple blood draw, and we would send the sample to the lab, and give you a call with the results over the phone. If the results are positive, we would want to have you come back in and talk to you about what the specific recommendations are, given what we find and which gene has a variant. If your test is negative or uncertain, we're also happy to meet with you again or speak over the phone to answer any questions you have about what the test means for you and your family.

We've gone over some genetics, and the genetic causes of cancers, including risks and testing options, as well as the test results, and what we would do with those results. Testing is a personal choice and is optional. Many people have conversations with family and other people before deciding whether or not to pursue testing. Hopefully it's been helpful to hear some of the information today.

Do you have any additional questions?

Given what we've talked about, would you want to do the genetic test? [Yes/No]

MEDIUM COMPLEXITY

Hello, my name is Mary, and I'm a genetic counselor. I've looked through your records and have a good idea of what brings you in today. We'll be talking about your sister's recent diagnosis of breast cancer and how we might think about your situation from a genetic standpoint. I have a plan for what might be helpful for us to talk about today.

I wonder if you could tell me in your own words what brings you in today?

Do you have any questions before we get started?

Thanks, it's helpful to know where you're coming from. I hope I can answer most of those questions. So, today we'll review what we know about the genetic causes of cancer, and how cancer can be passed on in certain families. We will go over breast cancer as well as other cancers--like ovarian cancer--that can come from the same genetic cause. Then, we can talk more about the genetic testing that we have available, and what kinds of results we can get from a genetic test. If you decide to have testing, your doctor may want you to change your medical care to help reduce your chance of getting cancer. This will depend on what the results show us. Because of the way cancer can be passed in families, your results may also affect other close family members, and they may also want to get tested.

What do you think about that plan? Anything else you'd like me to talk about?

Sounds good.

So, let's review what we know about what causes breast cancer and how it might be passed down in families. We'll also go over some basic genetics concepts.

When we think about who gets cancer, we usually don't know what caused the cancer. Cancer is multifactorial. That means that it can happen because of many causes like the environment, a person's lifestyle, as well as a person's genetics.

We know that only a small amount--5-10%--of cancer is thought to be hereditary, or running in families. In cancers that are running in families, only a small number have a genetic cause we can identify. Hereditary cancers are more likely to have individuals with younger onset cancer, multiple generations of family members affected, and multiple related cancers--such as breast and ovarian--in the same family.

In your case, we know that your sister was diagnosed at a younger age, in her 40s, which makes us wonder if she has a genetic change that caused her to get cancer.

Okay?

Our body is made up of thousands and thousands of cells. Every cell in our body contains our all of our genetic information. Our genetic information contains something called genes. Genes are the instructions that tell our body how to grow and develop, like giving us eye color or how curly our hair is. Genes help control the functions in our body. We each have two copies of every gene, one that we get from our mom, and one that we get from our dad.

Do you have any questions about that?

We know that there are certain genes that function to help prevent cancer. A few genes scientists have discovered, such as BRCA1 and BRCA2, are associated with a higher risk of getting breast cancer when something in one of those genes is changed so that the gene doesn't work properly. For instance, women who have a variant in one of these genes has a higher chance of getting breast and ovarian cancer compared to women who do not have a variant.

From researching many families with more cancer than average, we have discovered a few genes that can cause individuals to get cancer.

Have you heard of BRCA1 and BRCA2 before today? What have you heard or learned about?

Okay. Over the last 30 years, many women with early onset breast and ovarian cancers have had genetic testing. We now have a better idea of which gene variants can cause cancer.

Often, people with variants in these genes will get cancer at an earlier age, under the age of 50. The cancer can look a certain way. For example women with cancer due to BRCA1 variant are more likely to have triple negative breast cancer than women who don't have a BRCA1 variant.

Now, the variants that I'm talking about can happen in two ways. The first way is that

you can be born with a variant that came from your mom or your dad. In that case, that variant is present in all of the cells in your body. The second way a variant can occur in the body is that it can be acquired in a single cell at some point in a person's life.

Okay?

In order for cancer to develop, two variants actually need to be present. First in one copy of that gene, then in the other copy of that gene in the same cell, so that there are no working copies. When these genes don't work, cells can grow out of control, which turn into cancer and tumors in the tissue.

When there's one copy of a gene that has a variant, that makes someone a carrier. Being a carrier means that person has a predisposition to cancer. It's not a guarantee, because there is still one functioning copy. A second hit or a second variant in the other copy of the gene can happen. Then there are no working copies of the gene, and cancer is more likely to occur.

That was a lot of information about cancer and genetics--what questions do you have about that?

I'm not sure if I explained it all clearly--could you try to summarize what I said so that I can be sure that I got across the important information?

That seems about right. After our visit, I will send you a letter that has the main points of what we talked about today. Hopefully that will also help to answer your questions.

I'd now like to go over what testing we could offer you. It's usually best to test the affected person in a family first. That way, if the test is positive, we know what is causing the cancer in that person. We also know what test should be offered to the rest of the family. If it's negative, we know that there isn't a known genetic cause for the cancer at this time. We would know that we wouldn't be able to test other family members.

I see that your sister isn't interested in getting tested, and maybe that's something that you could talk to her about later, after her cancer treatment is over. We are still able to test you, even though it might be harder to interpret your results and what that means for your genetic risk for cancer. Either way, having a first degree relative increases your risk for developing cancer yourself. We'd like you to be on top of your mammograms and cancer screenings either way.

Does that make sense? What questions do you have about that?

The test we would offer you today is a cancer panel test which looks for variants or changes in ten genes we know we know can cause someone to get breast cancer. Variants in these genes can also indicate that you have a chance of getting other types of cancers. That includes ovarian, pancreatic, thyroid, melanoma, among others. The test looks for changes in the gene that causes it not to work properly, including changes to the spelling of the gene, or extra or missing pieces. These ten genes have been grouped together onto one test because there are specific professional guidelines for how to change medical care based on finding a variant in these ten genes. There may be cancer screening or surgical

options to consider.

The first two genes on the panel we know more about, BRCA1 and BRCA2, which I mentioned earlier. Variants in both of these genes predispose you to get breast and ovarian cancers. The risk for breast cancer in for people variants in BRCA1 or BRCA2 is up to 80-85% by age 70. The risk for getting ovarian cancer in BRCA1 is up to 39% by age 70, and BRCA2 is up to 17% by age 70. As we talked about earlier, these risks are much higher than for women who do not have variants in BRCA1 or BRCA2.

The other genes we are looking at are genes that have been reported in the literature as being associated with breast cancer, but may have a lower penetrance. A lower penetrance means that the risk for cancer would not be as high. As I mentioned, a few of them are associated with other types of cancer--ovarian, pancreatic, thyroid, melanoma--and there would be specific recommendations we would make for you based on what the genetic test tells us. Unfortunately, for some kinds of cancer, including ovarian cancer pancreatic cancer, there are no medically sensitive tests that can reliably detect early stage cancers.

The genetic test that we can offer won't be able to tell you when you will get cancer, or even if you will get cancer. None of the genes come with a 100% certainty that someone will get cancer if they have a variant in that gene. The uncertainty about whether or not you get cancer could potentially cause some worry and anxiety. It's important to think about what this test would mean for you.

Next, I'll go over the kinds of results you can get from this test, and what the results could mean for you and your family. But first, do you have any questions about what is included in the panel test?

So, from doing this genetic test, there can be three outcomes: positive, negative or uncertain.

The first outcome could be that the test is positive, and we have found a pathogenic variant in your DNA that predisposes you to developing breast cancer, and potentially other cancers in your lifetime.

If the test is positive, there would be specific medical recommendations and medical decisions for you to think about.

In that case, the first important thing to think about would be breast cancer screening. With a positive test, the recommendation is that you have breast mammograms and breast MRI. These would be done every six months, alternating. This helps detect breast cancer early. The MRI is another method of looking at the breast tissue. It can be useful in finding cancer in younger women as well as in women who have dense breast tissue.

Also, for someone like your sister who has already had breast cancer, a positive genetic test result would increase the chance for getting cancer in a brand-new spot in the same breast or in the other breast. Some women choose to remove both breasts with surgery to help prevent getting cancer. This way, that they don't have to do mammography and MRI every 6 months. Removing the breast tissue greatly reduces the chance of getting breast

cancer. It doesn't reduce it all the way to zero, though. There may be a few breast cells left over after surgery. Breast exams from your doctor would be a good way to continue look for breast cancer after removing both breasts. In women who choose to remove their breasts, many also choose to have breast reconstruction in same surgery.

If you were ever to get breast cancer, you could choose to have surgery to remove just the cancer cells, without removing the breast. After that you could continue doing screening to look for the cancer coming back, or for a new cancer in either breast.

Variants in some of these genes can also increase a woman's chance for ovarian cancer. If the test is positive and you have a variant in one of those genes, you would want to consider having surgery to remove your ovaries as well as your fallopian tubes. Unlike breast tissue, the ovaries and fallopian tubes (which can develop cancer) are harder to access. The current screening methods we have aren't very effective. If they pick up cancer it is often at a later stage. Because of this, we would recommend the removal of your ovaries after you are done having children, but by your late thirties or early 40s. Removing the ovaries not only greatly lowers the risk for ovarian cancer by 96%, but it also reduces the risk for breast cancer by 50%. However, removing the ovaries forces the body to go into premature menopause. That may not be ideal or comfortable. You can talk to your doctor about how you might manage those symptoms.

What questions do you have so far?

Okay. Also, if you were to test positive, we could begin offering genetic testing to your other family members who are at risk. We know that your close relatives, your parents, siblings, and children would have a 50%, like the flip of a coin, chance of having the same variant. Gene variants are usually passed on from generation to generation, and inherited from a parent. Both men and women can pass on the gene variants. Extended family members could also be at risk.

While breast cancer is more common in women, it can also happen in men. Men who carry a BRCA variant are at a higher risk of developing male breast cancer. They are also at an increased risk for developing prostate cancer.

You may have questions about testing children in the family. We don't recommend testing children under the age of 18. here are no increased risks for cancers in childhood in most of the genes we are testing. We recommend waiting until at least 18. At that age, they can make that decision for themselves. Even at 18, some people might not want to do genetic testing.

Overall, you should know that if the test comes back positive, we would make a plan for how to move forward for you and your family, to help prevent and detect cancer in the future.

We've gone over what we would do and think about if you had a positive results--can you tell me how you're thinking about all of this information and what you might do?

The second possible result could be a negative result. For you, this would mean that we did not find any variants in the genes we tested. As we talked about earlier, this does not

rule out the possibility that there is hereditary cancer running in your family. You would still be at increased risk above the general population given your family history of breast cancer at an early age in your sister. However, we can have some reassurance that we did not find any variants in the genes we tested.

If you get a negative result, there would be no specific change in your medical care. You would still need to be serious about getting screened for breast cancer. You should talk to your doctor about when to get mammograms. This would be the case even if you decide not to get testing at all.

It would be helpful to know if your sister had testing later and got a positive result. Because your test result was already negative, we would know that you did not inherit the same variant that she has from one of your parents. That would mean that you and your children would not have a higher chance of getting cancer. Your children cannot inherit something from you that you do not have.

What would the plan be if you got a negative result?

The third type of test result is a variant of uncertain significance. This means that we found something in one or more of the genes that we tested you for. But that we wouldn't be sure whether or not it increases your chance of getting cancer. Over time, scientists continue to do research. They continue to test people with and without cancer to determine which genetic variants are associated with cancer. As the lab collects more information, it is possible that they reclassify or relabel the variant as either positive or negative. They will contact us if and when that happens. We would pass the information on to you and your doctor. If your result has an uncertain variant, we would not recommend that you change your medical care, but that you should continue to get regular cancer screenings.

What would the plan be if you got an uncertain result?

That was a lot of information, do you have any questions about what I just went over about the three kinds of results?

I also want to talk to you about something called the Genetic Information Nondiscrimination Act or GINA. Genetic testing results are placed in the medical record. There is a law that protects people from being discriminated against based on their genetic information. This means that your employer and your health insurance company can't treat you differently based on your genetic test results. This law does not apply to long-term care, life insurance, and disability insurance. As of now, those kinds of insurance agencies can ask about genetic testing. They are also allowed to refuse to give you insurance based on that. They are also allowed to charge you more for insurance based on your genetic test results. For this reason, some people like to have their plans in place before having genetic testing. If you already have insurance, that would not be affected. I have not heard of anyone having a problem with this, but it is something to consider.

Any questions about that?

Okay. If you think this testing is something you'd like to do, we could do the test today. You can also go home to think about it or decide not to do testing at all at this point, knowing that you can always revisit the issue later. Logistically, it would be a simple blood draw, and we would send the sample to the lab, and give you a call with the results over the phone. If the results are positive, we would want to have you come back in and talk to you about what the specific recommendations are, given what we find and which gene has a variant. If your test is negative or uncertain, we're also happy to meet with you again or speak over the phone to answer any questions you have about what the test means for you and your family.

We've gone over some genetics, and the genetic causes of cancers, including risks and testing options, as well as the test results, and what we would do with those results. Testing is a personal choice and is optional. Many people have conversations with family and other people before deciding whether or not to pursue testing. Hopefully it's been helpful to hear some of the information today.

What other questions do you have?

Given what we've talked about, would you want to do the genetic test? [Yes/No]

LOW COMPLEXITY

Hello, my name is Mary, and I'm a genetic counselor. I've looked through your records and have a good idea of what brings you in today. We'll be talking about your sister's recent diagnosis of breast cancer and how we might think about your situation from a genetic standpoint.

I have a plan for what might be helpful for us to talk about today. I wonder if you could tell me in your own words what brings you in today?

What questions do you have s before we get started?

Thanks, it's helpful to know where you're coming from. I hope I can answer most of those questions. So, today we'll review what we know about the genetic causes of cancer, and how cancer can be passed on in certain families. We will go over breast cancer as well as other cancers--like ovarian cancer--that can come from the same genetic cause. Then, we can talk more about the genetic testing that we have available, and what kinds of results we can get from a genetic test. If you decide to have testing, your doctor may want you to change your medical care to help reduce your chance of getting cancer. This will depend on what the results show us. Because of the way cancer can be passed in families, your results may also affect other close family members, and they may also want to get tested.

We've gone over what we would do and think about if you had a positive results--can you tell me how you're thinking about all of this information and what you might do?

When you think about what causes cancer, what comes to mind?

That's a good answer. Why don't I review what we know about what can cause breast cancer and how it can be passed down in families.

When we think about who gets cancer, we usually don't know what caused the cancer. It could be the environment, a person's lifestyle, their genes, or all those things together. We know that most cancers are not hereditary and do not run in families. For those families that do have hereditary cancers, only a small percent are caused by changes in genes.

Do you have any questions about that?

Genes are the instructions that tell our body how to grow and develop, like what color our eyes are or how curly our hair is. Genes have specific functions in our body. We get our genes from our parents.

We know that there are certain genes that work to help prevent cancer. When these genes don't work, cells can grow out of control, which turn into cancer and tumors in the body. Women who have a change or variant in one of these genes that keep the genes from working have a higher chance of getting breast and ovarian cancer compared to women who do not have that kind of variant. Often, people with variants in these genes will get cancer at an earlier age, under the age of 50. The cancer may also have certain features.

I'm not sure if I explained it all clearly--could you try to summarize what I said so that I can be sure that I gave you the important information?

How does this information help you think about your sister's cancer?

That seems about right. After our visit, I'll send you a letter that has the main points of what we talked about today. Hopefully that will also help to answer your questions.

Let's go over what testing we could offer you. It's usually best to test a person who has been affected with cancer first. I see that your sister isn't interested in getting tested. Maybe that's something that you could talk to her about later, after her cancer treatment is over. You should know that it might be harder to know what your results would mean for your risk for cancer if we don't have your sister's results first. However, we are still able to test you. There is a chance that you would get results that would be helpful to you.

Having a close relative with breast cancer (your sister) increases your risk for getting breast cancer yourself. We'd like you to be on top of your mammograms and cancer screenings no matter what genetic testing might tell us.

Does that make sense?

The test we would offer you today is a cancer panel test. The panel test looks for variants in ten genes we know can cause someone to get breast cancer. Variants in these genes can also show that you have a chance of getting other types of cancers. For some of the genes, like BRCA1 and BRCA2, we have a good idea of how high the risk of cancer could be. For others, we're still learning and will not have as much information to share. All the genes we are testing are known to cause breast cancer in some people. Depending

on the result, your doctor might want to change how you're screened for cancer. There may also be surgeries to consider to help prevent you from getting cancer.

The genetic test that we can offer won't be able to tell you when you will get cancer, or even if you will get cancer. None of the genes come with a 100% certainty that someone will get cancer, even if they have a variant in that gene. The uncertainty about whether you will get cancer could potentially cause you some worry and anxiety. It's important to think about what this test would mean for you.

Next, I'll go over the kinds of results you can get from this test, and what the results could mean for you and your family. But first, what questions do you have about what is included in the panel test?

So, this genetic test can have three kinds of results: positive results, negative results, or uncertain results.

First, let's talk about a positive result. A positive result means the test found a variant in one of the genes that could cause you to get breast cancer--and maybe other cancers--at some point in your life.

If the test is positive, there are specific medical care changes and medical decisions for you to think about.

In that case the first important thing to think about would be breast cancer screening. With a positive test, the recommendation is that you have breast mammograms and breast MRI. These would be done every six months, alternating. This helps ensure that if you get breast cancer, it is detected early. The MRI is another way of looking at the breast tissue. It can be useful in finding cancer in younger women and women who have dense breast tissue.

Also, for someone like your sister who has already had breast cancer, a positive genetic test result would increase the chance for getting cancer in a brand-new spot in the same breast or in the other breast. Some women choose to remove both breasts with surgery to help prevent getting cancer. Removing both breasts greatly decreases the chance of getting breast cancer. It doesn't decrease it all the way to zero, though.

If you were ever to get breast cancer, you could choose to have surgery to remove just the cancer cells, without removing the breast. After that you could continue doing screening to look for the cancer coming back, or for a new cancer in either breast.

These would be choices that you could talk about further if your genetic testing shows a positive result.

Variants in some of these genes can also increase a woman's chance for ovarian cancer. If you have a variant in one of those genes, you would want to consider having surgery to remove your ovaries as well as your fallopian tubes. The way we can screen for ovarian cancer isn't very effective. So, it's hard to find ovarian cancer at an early stage. Doctors recommend taking out your ovaries and fallopian tubes after you are done having children to lower the chance of getting cancer. This decreases your chance of getting

ovarian cancer and lowers the chance of getting breast cancer.

There are downsides to consider, though. Removing your ovaries forces your body to go into menopause earlier than you would have. That may not be ideal or comfortable. You'll be able to talk to your doctor about how you might manage those symptoms.

What questions do you have so far?

Okay. If you tested positive, we could begin offering genetic testing to your other family members who are at risk. Gene variants are usually passed on through families, from mothers or fathers to their children. Both men and women can pass on the gene variants. Your close relatives--your parents, brothers and sisters, and children--would have a 50/50 chance of having the same variant. It's like the flip of a coin. Other, more distant relatives could also be at risk.

While breast cancer is more common in women, it can also happen in men. Men who carry a BRCA variant are at a higher risk of getting breast cancer. They are also at increased risk for getting prostate cancer.

You may have questions about testing children in the family. We don't recommend testing children under the age of 18. There are no increased risks for cancers in childhood in most of the genes we are testing. We recommend waiting until at least 18. At that age, they can make that decision for themselves. Even at 18, some people might not want to do genetic testing.

Overall, you should know that if the test comes back positive, we would make a plan for how to move forward for you and your family, to help prevent and detect cancer in the future.

We've gone over what we would do and think about if you had a positive results--can you tell me what the plan would be for you if you got a positive result?

What about for your family?

If you get a negative result, there would be no change in your medical care. But you would still need to be serious about getting screened for breast cancer because of your family history. You should talk to your doctor about when to get mammograms. This would be the case even if you decide not to get testing at all.

It would be helpful to know if your sister had testing later and got a positive result. Because your test result was already negative, we would know that you did not inherit the same variant that she has from one of your parents. That would mean that you and your children would not have a higher chance of getting cancer. Your children cannot inherit something from you that you do not have.

What do you think your plan would be if you got a negative result?

The third type of test result is a variant of uncertain significance. This would mean that we found a change in one of the genes that we tested you for. But, we wouldn't be sure whether or not it increases your chance of getting cancer. Over time, scientists continue

to do research. They keep testing people with and without cancer to see which variants are related to cancer and which ones are not. As the lab collects more information, it's possible that they will later label the variant as positive or negative. They will contact us if and when that happens. We would then pass the information on to you and your doctor. If your result has an uncertain variant, we would not recommend that you change your medical care. You should continue to get regular cancer screenings.

What do you think your plan would be if you got an uncertain result?

I also want to talk to you about something called the Genetic Information Nondiscrimination Act or GINA. Genetic testing results are placed in the medical record. There is a law that protects people from being discriminated against based on their genetic information. This means that your employer and your health insurance company can't treat you differently based on your genetic test results. This law does not apply to long-term care, life insurance, and disability insurance. As of now, those kinds of insurance agencies can ask about genetic testing. They are also allowed to refuse to give you insurance based on that. They are also allowed to charge you more for insurance based on your genetic test results. For this reason, some people like to have their plans in place before having genetic testing. If you already have insurance, that would not be affected. I have not heard of anyone having a problem with this, but it is something to consider.

What questions do you have about that?

Okay. We've gone over what we know about genetics and cancer. We also talked about genetic testing that you could have and what we would do with the results. You should know that testing is a personal choice and is optional. Many people choose to talk with family and other people before deciding whether to have testing. Hopefully it's been helpful to hear some of the information today.

What other questions do you have?

Given what we've talked about, would you want to do the genetic test? [Yes/No]

APPENDIX E: Bivariate Analyses

Table 41. Correlations between Independent Variables

Pairwise Pearson's correlations were performed to examine correlations between independent variables (personal characteristics). Shown are correlation coefficients and p-values.

	Age	Non-Caucasian Race	Education	Income	Number of Biological Children	Perceived Personal Risk of Cancer	Family History	GLAC	PPOS
Age	1.0000								
Non-Caucasian Race	**-0.2504*** **0.0001**	1.0000							
Education	0.0598 0.3447	**-0.2276*** **0.0001**	1.0000						
Income	**0.2072*** **0.0009**	**-0.1720*** **0.0035**	**0.3346*** **0.0000**	1.0000					
Number of Biological Children	**0.3854*** **0.0000**	0.0301 0.6129	**-0.1329** 0.0248	0.2050* 0.0005	1.0000				
Perceived Personal Risk of Cancer	-0.0853 0.1781	**-0.1534*** **0.0095**	0.0569 0.3384	0.0176 0.7678	**-0.1512*** **0.0107**	1.0000			
Family History	0.0098 0.8774	-0.0531 0.3709	-0.0203 0.7327	-0.0168 0.7769	0.0062 0.9175	0.1053 0.0759	1.0000		
GLAC	0.0786 0.2135	**-0.2330*** **0.0001**	**0.3357*** **0.0000**	0.1127 0.0570	**-0.1185*** **0.0457**	0.1145 0.0536	0.1000 0.0913	1.0000	
PPOS	**0.3468*** **0.0000**	**-0.2131*** **0.0003**	**0.2149*** **0.0003**	**0.1714*** **0.0037**	**0.1781*** **0.0025**	-0.1030 0.0826	-0.0118 0.8429	**0.2102*** **0.0003**	1.0000

Table 42. Pearson's Pairwise Correlations of Personal Characteristics by Outcomes

First line: Pearson's Correlation Coefficient
Second line: *p*-value

	Age	Non-Caucasian Race	Education	Household Income	Number of Biological Children	Perceived Personal Risk	Family History	GLAC	PPOS
Decisional Conflict	-0.0686	**0.1226***	-0.1001	-0.1050	-0.0695	0.0874	0.0137	**-0.1873***	-0.0374
	0.2797	**0.0393**	0.0929	0.0778	0.2447	0.1434	0.8185	**0.0015**	0.5311
Respect	0.0729	-0.0112	0.0214	0.1094	0.0990	-0.0722	0.0668	0.0864	0.0121
	0.2486	0.8501	0.7186	0.0647	0.0952	0.2246	0.2601	0.1451	0.8380
Satisfaction	-0.0109	0.0308	0.0216	**0.1208***	0.1124	-0.0349	0.0154	**0.1338***	-0.0917
	0.8628	0.6041	0.7161	**0.0412**	0.0580	0.5570	0.7951	**0.0237**	0.1217
Knowledge	**0.1305***	**-0.3630***	**0.1843***	**0.1900***	0.0255	0.0384	-0.0364	**0.3392***	**0.2055***
	0.0384	**0.0000**	**0.0018**	**0.0012**	0.6685	0.5181	0.5403	**0.0000**	**0.0005**
Ease	-0.0319	-0.0335	-0.0254	0.0054	-0.0657	-0.0769	0.0369	0.0088	-0.0155
	0.6155	0.5736	0.6699	0.9282	0.2707	0.1973	0.5355	0.8824	0.7950
Reality	0.1089	-0.0346	-0.0438	**0.1658***	**0.1690***	-0.0063	0.1003	0.0609	-0.0744
	0.0858	0.5624	0.4625	**0.0052**	**0.0044**	0.9160	0.0921	0.3069	0.2118
Similarity	-0.0401	0.0830	-0.0752	0.0128	0.0512	-0.0515	0.0492	0.0772	**-0.1355***
	0.5296	0.1654	0.2087	0.8303	0.3936	0.3906	0.4110	0.1970	**0.0231**
Engagement	0.0030	-0.0484	0.0489	0.0284	-0.0945	-0.0075	0.0899	**0.1530***	0.0378
	0.9627	0.4156	0.4111	0.6327	0.1121	0.8997	0.1300	**0.0097**	0.5249
Negative Emotion	-0.0927	0.1031	-0.0971	0.0112	0.0132	**0.1322***	0.0412	**-0.2071***	-0.0346
	0.1423	0.0817	0.1012	0.8506	0.8244	**0.0257**	0.4874	**0.0004**	0.5598
Positive Emotion	0.1236	-0.0246	-0.0540	0.0833	-0.0020	-0.0246	0.0912	0.0877	**-0.1560***
	0.0500	0.6786	0.3628	0.1602	0.9729	0.6795	0.1240	0.1388	**0.0082**

Table 43. High Complexity Correlations of Personal Characteristics by Outcomes

First line: Pearson's Correlation Coefficient
Second line: *p*-value

	Age	Non-Caucasian Race	Education	Household Income	Number of Biological Children	Perceived Personal Risk	Family History	GLAC	PPOS
Decisional Conflict	-0.0503	0.0939	-0.0608	-0.1185	0.0139	0.0473	-0.0150	-0.0834	-0.0460
	0.6517	0.3735	0.5650	0.2605	0.8955	0.6543	0.8874	0.4292	0.6636
Respect	-0.0383	-0.0172	0.1190	0.0553	-0.0293	-0.1506	0.1246	**0.3117***	-0.0150
	0.7291	0.8702	0.2559	0.5987	0.7804	0.1496	0.2340	**0.0024**	0.8864
Satisfaction	-0.0863	0.1037	0.1254	0.1738	0.0349	0.0562	0.0692	**0.2652***	-0.0681
	0.4351	0.3224	0.2310	0.0956	0.7400	0.5928	0.5099	**0.0102**	0.5166
Knowledge	0.1430	**-0.3965***	**0.2884***	0.1648	0.0028	0.1701	-0.0735	**0.4328***	0.0724
	0.1945	**0.0001**	**0.0051**	0.1144	0.9790	0.1031	0.4838	**0.0000**	0.4901
Ease	-0.0253	0.0064	0.0530	0.0502	-0.0587	-0.1241	-0.0412	0.0863	0.1189
	0.8191	0.9514	0.6161	0.6347	0.5785	0.2386	0.6963	0.4134	0.2589
Reality	0.0752	0.1012	-0.0122	0.1468	0.1707	0.0146	0.1266	**0.2284***	-0.0563
	0.4993	0.3373	0.9079	0.1627	0.1038	0.8902	0.2292	**0.0286**	0.5942
Similarity	-0.1376	0.1114	-0.0670	0.0094	0.0762	0.0368	-0.0919	0.0537	-0.1535
	0.2149	0.2904	0.5257	0.9288	0.4704	0.7278	0.3836	0.6111	0.1440
Engagement	0.0603	**-0.2369***	0.1881	0.0604	**-0.2886***	-0.0664	0.0989	0.1877	0.0231
	0.5856	**0.0223**	0.0709	0.5651	**0.0050**	0.5274	0.3454	0.0716	0.8259
Negative Emotion	**-0.2153***	0.1766	-0.1150	-0.0204	0.0351	0.1300	0.1313	-0.1601	-0.0244
	0.0492	0.0905	0.2725	0.8459	0.7383	0.2141	0.2097	0.1252	0.8165
Positive Emotion	**0.2560***	-0.0455	0.0849	0.1084	-0.0570	-0.0053	0.0733	0.1569	-0.0672
	0.0188	0.6647	0.4185	0.3010	0.5876	0.9597	0.4849	0.1332	0.5223

Table 44. Medium Complexity Correlations of Personal Characteristics by Outcomes

First line: Pearson's Correlation Coefficient
Second line: *p*-value

	Age	Non-Caucasian Race	Education	Household Income	Number of Biological Children	Perceived Personal Risk	Family History	GLAC	PPOS
Decisional Conflict	-0.0118	0.0929	**-0.3171***	**-0.2178***	0.0200	0.1578	0.0962	**-0.2897***	-0.0589
	0.9149	0.3679	**0.0016**	**0.0331**	0.8466	0.1247	0.3510	**0.0042**	0.5687
Respect	0.1097	-0.1208	0.0759	**0.2287***	0.1015	-0.1548	-0.0736	-0.1140	0.1098
	0.3205	0.2385	0.4602	**0.0242**	0.3223	0.1300	0.4735	0.2661	0.2843
Satisfaction	-0.0432	-0.0428	0.0468	0.1509	0.1383	-0.1917	-0.0974	0.0100	0.0091
	0.6962	0.6773	0.6492	0.1401	0.1767	0.0599	0.3427	0.9222	0.9298
Knowledge	0.1723	**-0.2798***	0.1743	**0.2184***	0.1139	0.0208	-0.0480	**0.3391***	**0.4106***
	0.1170	**0.0055**	0.0878	**0.0316**	0.2668	0.8397	0.6406	**0.0007**	**0.0000**
Ease	-0.0762	0.0608	-0.1247	-0.0047	-0.1094	-0.0668	0.1637	0.0053	-0.1037
	0.4937	0.5564	0.2260	0.9636	0.2886	0.5178	0.1109	0.9590	0.3146
Reality	0.0556	-0.0444	0.0430	**0.2179***	0.0511	-0.0840	0.0634	-0.0543	-0.1320
	0.6152	0.6674	0.6775	**0.0329**	0.6212	0.4157	0.5395	0.5996	0.2000
Similarity	-0.0169	0.1567	-0.0684	-0.0725	-0.0442	-0.1559	0.0889	0.0682	**-0.2647***
	0.8798	0.1294	0.5101	0.4852	0.6705	0.1314	0.3918	0.5115	**0.0095**
Engagement	-0.0601	0.1143	-0.1600	0.0310	0.0022	-0.0525	0.1595	0.1033	0.0752
	0.5892	0.2673	0.1195	0.7644	0.9828	0.6113	0.1205	0.3167	0.4667
Negative Emotion	0.0164	0.1283	**-0.2128***	-0.0391	0.0262	0.1622	-0.0354	**-0.3666***	-0.1694
	0.8823	0.2105	**0.0364**	0.7036	0.7993	0.1125	0.7307	**0.0002**	0.0972
Positive Emotion	-0.0203	0.0568	-0.1100	0.0010	-0.1274	0.0202	0.0990	0.0460	**-0.2207***
	0.8546	0.5803	0.2836	0.9922	0.2137	0.8447	0.3347	0.6545	**0.0299**

Table 45. Low Complexity Correlations of Personal Characteristics by Outcomes

First line: Pearson's Correlation Coefficient
Second line: *p*-value

	Age	Non-Caucasian Race	Education	Household Income	Number of Biological Children	Perceived Personal Risk	Family History	GLAC	PPOS
Decisional Conflict	-0.1461	0.1869	0.0958	0.0114	**-0.2789***	0.1065	-0.0449	-0.1743	0.0132
	0.1874	0.0697	0.3558	0.9125	**0.0065**	0.3068	0.6658	0.0912	0.8993
Respect	0.1316	0.1105	-0.1310	0.0341	**0.2236***	0.0651	0.1667	0.1013	-0.0763
	0.2327	0.2838	0.2033	0.7414	**0.0294**	0.5305	0.1046	0.3261	0.4601
Satisfaction	0.1169	0.0260	-0.1460	0.0245	0.1889	0.0190	0.0801	0.1288	**-0.2313***
	0.2895	0.8018	0.1558	0.8131	0.0667	0.8549	0.4377	0.2111	**0.0233**
Knowledge	0.0730	**-0.4216***	0.0778	0.1853	-0.0540	-0.0829	0.0155	**0.2538***	0.1105
	0.5095	**0.0000**	0.4510	0.0706	0.6032	0.4247	0.8807	**0.0126**	0.2840
Ease	0.0025	-0.1491	0.0168	-0.0243	-0.0541	-0.0353	-0.0109	-0.0626	-0.0456
	0.9820	0.1470	0.8708	0.8139	0.6025	0.7339	0.9163	0.5446	0.6594
Reality	0.2124	-0.1695	-0.1661	0.1315	**0.3021***	0.0540	0.1091	0.0049	-0.0272
	0.0539	0.1006	0.1077	0.2039	**0.0031**	0.6053	0.2924	0.9625	0.7936
Similarity	0.0515	-0.0212	-0.1055	0.0839	0.1510	0.0010	0.1417	0.1103	0.0420
	0.6457	0.8395	0.3117	0.4214	0.1486	0.9926	0.1731	0.2898	0.6881
Engagement	0.0084	-0.0223	0.1089	-0.0061	0.0132	0.0938	0.0088	0.1700	0.0140
	0.9397	0.8294	0.2907	0.9532	0.8989	0.3659	0.9324	0.0977	0.8925
Negative Emotion	-0.0903	-0.0070	0.1053	0.1217	-0.0580	0.1146	0.0406	-0.0744	0.1342
	0.4141	0.9462	0.3074	0.2375	0.5766	0.2690	0.6942	0.4714	0.1923
Positive Emotion	0.1264	-0.0838	-0.1543	0.1346	0.2000	-0.0725	0.1021	0.0594	-0.1751
	0.2518	0.4168	0.1333	0.1912	0.0520	0.4852	0.3221	0.5654	0.0879

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EDUCATION

Johns Hopkins University/NHGRI | ScM in Genetic Counseling **8/2015-1/2018**
- Anticipated Graduation Date: January 19, 2018

University of Washington | Non-Matriculated Student **2011-2012, 2014**
- Graduate coursework in Advanced Human Genetics, 2014
- Certificate in Applied Biostatistics, online, 2011-2012

University of Chicago | BA in Biological Sciences, specialization in Neuroscience **2008-2011**
- Dean's List 2008-2010

University of Michigan - Ann Arbor **2007-2008**
- University Honors 2007

GENETIC COUNSELING CLINICAL AND LABORATORY ROTATION EXPERIENCE

Inova | Cardiovascular Genomic Center and Translational Medicine Institute **10-12/2017**
- 8 week rotation in in adult cardiac genetics, pediatric genetics, and inpatient pediatric genetics

National Institutes of Health | National Eye Institute **8-10/2017**
- 8 week rotation in genetic conditions of the eye

Walter Reed National Military Medical Center | Genetics Services **8-10/2017**
- 6 week rotation in general and pediatric genetics

National Institutes of Health | National Institute of Neurologic Disorders and Stroke **6-8/2017**
- 6 week rotation in adult neurogenetics

Johns Hopkins Hospital | Institute of Genetic Medicine **3-5/2017**
- 8 week rotation in general adult and pediatric genetics, and specialty clinics in connective tissue disorders and neuromuscular disorders (MDA)

Johns Hopkins Hospital | Sidney Kimmel Comprehensive Cancer Center **8-12/2016**
- 16 week rotation in the Clinical Cancer Genetics and Prevention and GI clinics
- Attendance and participation in case conferences and GAITWAY molecular tumor boards

University of Cape Town | Groote Schuur Red Cross Children's Hospital **6-7/2016**
- 6 week full-time rotation in prenatal, pediatric, cancer, adult general genetics, hematology, cardiology, cystic fibrosis, and neurogenetics specialty clinics
- Attended Huntington's Association of South Africa support group

National Institutes of Health | Undiagnosed Disease Program **4-5/2016**
- 4 week rotation in pediatric undiagnosed diseases

GeneDx **3-4/2016**
- 4 week rotation learning clinical commercial laboratory practices and protocols
- Presentation of *TTN* phenotype and genetic testing information to patient support group

Maternal Fetal Medicine Associates of Maryland **1-3/2016**
- 8 week rotation in prenatal cases in a private practice setting

MedStar Washington Hospital Center | Women's and Infants' Services **10-12/2015**
- 8 week rotation in primarily high-risk prenatal cases, with some cancer, neurology and endocrine cases

RESEARCH EXPERIENCE

NIH National Human Genome Research Institute | Social and Behavioral Research Branch
Master's Thesis Project: *"Effects of Communication Style on Analogue Clients in a Video Cancer Genetic Counseling Session", Advisor: Lori Erby, PhD CGC* **2017-Present**
- Design, implementation, and analysis of project investigating how communication of information in genetic counseling affects participant affective and cognitive outcomes

Johns Hopkins School of Public Health | Berman Institute of Bioethics **6/2017-11/2017**
Summer Internship, *PI: Debra Mathews, PhD MA*

- Investigated approaches to informed consent and return of results of research genome sequencing to individuals with ALS and their family members
- Attended Institutional Review Board (IRB) and Institutional Stem Cell Research Oversight committee meetings

University of Washington | Departments of Medical Genetics and Neurology **7/2012-8/2015**
Research Scientist Assistant, *PIs: Dr. Wendy Raskind and Dr. Dong-Hui Chen*

- Investigated the genetic mechanisms of neurodegenerative diseases and movement disorders
- Performed exome data and variant interpretation for gene discovery, PCR sequencing, plasmid preparation, cell culture, virus transfection, cloning, mutagenesis and transformation, DNA and protein extraction, Western blot, microscopy, and other molecular biology and genetics functional assays
- Performed statistical analysis of transgenic mouse model behavioral data and other project data
- Mentored and trained undergraduate students

University of Chicago | Department of Psychiatry and Behavioral Neuroscience **11/2010-6/2011**
Research Assistant, *Human Behavioral Pharmacology Laboratory, PI: Dr. Harriet de Wit*

- Completed independent research project on human impulsivity and reward sensitivity
- Contributed to study design and IRB protocol and amendment writing; ran test subjects; collected and analyzed behavioral data using SPSS; prepared final report and presentation

University of Chicago | Department of Human Genetics **12/2009-4/2010**
Research Assistant, *Howard Hughes Medical Institute, PI: Dr. Bruce Lahn*

- Investigated immortal cell lines and cell fate determination and differentiation
- Performed general molecular biology laboratory procedures including PCR, DNA isolation and cloning, gel electrophoresis, plasmid extraction, virus growth and transfection, and cell culture

Smithsonian National Museum of Natural History | Departments of Marine Zoology and Education
Visiting Scientist Intern*, PI: Dr. Jerry Harasewych* **8-9/2009**

- Assisted marine zoologist in analyzing genetic sequences of marine gastropods; catalogued snail specimens

Education Intern

- Assisted in content development for the Human Origins Project website; researched evolution of early human ancestors

ADVOCACY AND SERVICE

King County Crisis Line | Volunteer Phone Worker and Trainer **3/2012-8/2015**

- Provided emotional support, mental health resources, and social service referrals to callers
- Trained incoming volunteers through role plays, facilitating group discussion, and providing constructive feedback and coaching
- Over 700 hours served

University of Washington | Genomics Outreach for Minorities (UW GenOM) **8/2014**
Writing Tutor

- Provided guidance to pre-college students on summer research papers and posters for projects in genetics, genomics, and engineering

Planned Parenthood of the Great Northwest | Young Professional Member/Volunteer **2011-2013**

- Attended and volunteered at events including Washington Reproductive Health Lobby Day, the National Medical Conference and Forum on Family Planning, Roe v. Wade 40th Anniversary Celebration, and others; developed print and digital marketing materials for fundraising events

UW Disability Studies Program | Attended disability-focused seminars and events **2014-2015**
Seattle Area Ataxia Foundation | Volunteered at "Walk n' Roll for Ataxia" charity event **9/2014**
Special Olympics Washington | Volunteered at regional swimming event **4/2014**
Community Health Clinic | Volunteered at a clinic for uninsured Chicago residents **4-6/2011**
Global Medical Brigade | Assisted in providing medical care in rural Honduras **6/2010**
Alternative Spring Break | Assisted impoverished community in rural Maine **2/2008**

GENETIC COUNSELING SHADOWING

Swedish Hospital | Robert Resta and Nancy Hanson at True Family Women's Cancer Center
Seattle Children's Hospital | Katie Golden-Grant

OTHER GENETIC COUNSELING AND RELEVANT EXPERIENCE

University of Chicago | Attended Maclean Conference on Clinical Medical Ethics	**11/2010, 11/2017**
NSGC | Attended annual educational conference	**9/2016, 9/2017**
Proteus Syndrome Foundation | Attended patient and family conference	**10/2017**
CSER | Attended Fall 2016 In-Person meeting in Bethesda, MD	**9/2016**
USA Science and Engineering Expo | Volunteer at NSGC booth	**4/2016**
Sarah Lawrence College | Genetic Counseling Career Day	**6/2014**

COMPUTER APPLICATIONS AND SKILLS

Electronic Medical Records | Epic Software
General | MS Office (including Excel) and Mac OS
Statistical Software | STATA, GraphPad InStat and Prism, and SPSS
DNA Software | Sequencher and DNA alignment programs including Clustal, MUSCLE, and BLAST
Variant Interpretation and Databases | PubMed, GenBank, NCBI, Ensembl, UCSC Genome Browser, variant servers, and related

OTHER ACTIVITIES

Music Ensemble Experience (flute) | Johns Hopkins Concert Orchestra (2015-2017); Northwest Mahler Festival (2014); Chicago Classical Symphony Orchestra (2010); UChicago Chamber Orchestra, Wind Ensemble, and Chamber Music Program (2008-2009, 2010-2011, 2008-2011, respectively); U of M Campus Philharmonic Orchestra (2007-2008)
Undergraduate Involvements | Phoenix Biological Society (UChicago, 2009-2011); College Democrats, Undergraduate Psychological Society (U of M, 2007-2008)

PUBLICATIONS

Dong-Hui Chen, Jennifer E. Below, Akiko Shimamura, Sioban B. Keel, Mark Matsushita, John Wolff, Youngmee Sul, **Emily Bonkowski**, Maria Castella, Toshiyasu Taniguchi, Deborah Nickerson, Thalia Papayannopoulou, Thomas D. Bird, Wendy H. Raskind. "Ataxia-pancytopenia syndrome is caused by missense mutations in SAMD9L." *American Journal of Human Genetics.* 98.6 (2016): 1146-1158.

Dong-Hui Chen, Aurélie Méneret, Jennifer R. Friedman, Olena Korvatska, Alona Gad, **Emily S. Bonkowski**, Holly A. Stessman, Diane Doummar, Cyril Mignot, Mathieu Anheim, Sanford Bernes, Marie Y. Davis, Nathalie Damon Perriere, Bertrand Degos, David Grabli, Domitille Gras, Fuki M. Hisama, Katherine M. Mackenzie, Phillip D. Swanson, Christine Tranchant, Marie Vidailhet, Steven Winesett, Trouillard Oriane, Laura M. Amendola, Michael O. Dorschner, Michael D Weiss, Evan E. Eichler, Ali Torkamani, Emmanuel Rose, Thomas D. Bird, and Wendy Herlihy Raskind. "ADCY5-related dyskinesia: broader spectrum and genotype/phenotype correlations." *Neurology*. 85.23 (2015): 2026-035.

Ying-Zhang Chen, MD, PhD, Jennifer R. Friedman, MD, Dong-Hui Chen, MD, PhD, Guy C.-K. Chan, PhD, Cinnamon S. Bloss, PhD, Fuki M. Hisama, MD, Sarah E. Topol, RN, Andrew R. Carson, PhD, Phillip H. Pham, BS, **Emily S. Bonkowski**, BS, Erick R. Scott, MD, Janel K. Lee, BS, Guangfa Zhang, PhD, Glenn Oliveira, BS, Jian Xu, PhD, Ashley A. Scott-Van Zeeland, PhD, Qi Chen, PhD, Samuel Levy, PhD, Eric J. Topol, MD, Daniel Storm, PhD, Phillip D. Swanson, MD, PhD, Thomas D. Bird, MD, Nicholas J. Schork, PhD, Wendy H. Raskind, MD, PhD, Ali Torkamani, PhD. "Gain-of-Function ADCY5 Mutations in Familial Dyskinesia with Facial Myokymia." *Annals of Neurology.* 75.4 (2014): 542-9.

Chen, Dong-Hui, Alipi Naydenov, Jacqueline L. Blankman, Heather C. Mefford, Marie Davis, Youngmee Sul, A. Samuel Barloon, **Emily Bonkowski**, John Wolff, Mark Matsushita, Corrine Smith, Benjamin F. Cravatt, Ken Mackie, Wendy H. Raskind, Nephi Stella, and Thomas D. Bird. "Two Novel Mutations In: Expansion of the Mutation Spectrum in PHARC and Assessment of Their Functional Effects." *Human Mutation.* 34.12 (2013): 1672-678.

Korvatska, O., N. S. Strand, J. D. Berndt, T. Strovas, D.-H. Chen, J. B. Leverenz, K. Kiianitsa, I. F. Mata, E. Karakoc, J. L. Greenup, **E. Bonkowski**, J. Chuang, R. T. Moon, E. E. Eichler, D. A. Nickerson, C. P. Zabetian, B. C. Kraemer, T. D. Bird, and W. H. Raskind. "Altered Splicing of ATP6AP2 Causes X-linked Parkinsonism with Spasticity (XPDS)." *Human Molecular Genetics*. 22.16 (2013): 3259-268.